

Cowey, Eileen Stewart (2016) *Using an end-of-life care pathway in acute stroke: a mixed methods study of decision-making and care experiences*. PhD thesis.

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**Using an end-of-life care pathway in acute stroke: a mixed
methods study of decision-making and care experiences.**

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Submitted in fulfilment of the requirements for the Degree of PhD

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October 2016

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Abstract

Background

The evidence base on end-of-life care in acute stroke is limited, particularly with regard to recognising dying and related decision-making. There is also limited evidence to support the use of end-of-life care pathways (standardised care plans) for patients who are dying after stroke.

Aim

This study aimed to explore the clinical decision-making involved in placing patients on an end-of-life care pathway, evaluate predictors of care pathway use, and investigate the role of families in decision-making. The study also aimed to examine experiences of end-of-life care pathway use for stroke patients, their relatives and the multi-disciplinary health care team.

Methods

A mixed methods design was adopted. Data were collected in four Scottish acute stroke units. Casenotes were identified prospectively from 100 consecutive stroke deaths and reviewed. Multivariate analysis was performed on casenote data. Semistructured interviews were conducted with 17 relatives of stroke decedents and 23 healthcare professionals, using a modified grounded theory approach to collect and analyse data. The VOICES survey tool was also administered to the bereaved relatives and data were analysed using descriptive statistics and thematic analysis of freetext responses.

Results

Relatives often played an important role in influencing aspects of end-of-life care, including decisions to use an end-of-life care pathway. Some relatives experienced

enduring distress with their perceived responsibility for care decisions. Relatives felt unprepared for and were distressed by prolonged dying processes, which were often associated with severe dysphagia. Pro-active information-giving by staff was reported as supportive by relatives. Healthcare professionals generally avoided discussing place of care with families. Decisions to use an end-of-life care pathway were not predicted by patients' demographic characteristics; decisions were generally made in consultation with families and the extended health care team, and were made within regular working hours.

Conclusion

Distressing stroke-related issues were more prominent in participants' accounts than concerns with the end-of-life care pathway used. Relatives sometimes perceived themselves as responsible for important clinical decisions. Witnessing prolonged dying processes was difficult for healthcare professionals and families, particularly in relation to the management of persistent major swallowing difficulties.

(Word count 92,605)

Table of contents

Abstract	2
Table of contents	4
List of tables	11
List of figures	13
List of text boxes	14
List of appendices	15
Thesis synopsis	16
Acknowledgements	18
Declaration	19
List of publications.....	20
List of abbreviations.....	21
Chapter 1 - Introduction	22
1.1 Personal motivation for conducting the study	22
1.2 Study aims	23
Chapter 2 - Literature Review	25
2.1 Outline of the literature review	25
2.2 Key definitions	26
2.3 Search strategy	27
2.3.1 Search results	29
2.4 Defining the LCP.....	30
2.5 Evaluating the LCP	32
2.6 The rise of the LCP	33
2.7 The evidence base for end-of-life care pathway effectiveness.....	34
2.8 Background to the study	40
2.8.1 Mortality, end-of-life care and stroke	40
2.8.2 Policy context at the beginning of this study	42
2.8.3 Guidance for end-of-life care after stroke	43
2.8.4 Advance directives and ‘living wills’	44
2.8.5 End-of-life care quality	45
2.8.6 Theoretical concepts in end-of-life care.....	49
2.8.7 Attitudes to death and dying	54
2.8.8 Summary	55
2.9 Recognising dying	55

2.9.1	Prognostication after stroke.....	57
2.9.2	Recognising dying in acute stroke care.....	60
2.9.3	Timing and the recognition of dying.....	62
2.9.4	Recognising dying – summary.....	64
2.10	Decision-making.....	65
2.10.1	Shared decision-making.....	65
2.10.2	Family involvement in end-of-life decision-making.....	67
2.10.3	Families and end-of-life decision-making in stroke care.....	69
2.10.4	The role of healthcare professionals in deciding end-of-life care.....	72
2.10.5	Decision-making - summary.....	74
2.11	Patient and family experiences of the LCP.....	75
2.12	Healthcare professionals’ experiences of LCP use.....	80
2.13	Preferred place of end-of-life care after stroke.....	84
2.14	Challenges in end-of-life care after stroke.....	85
2.14.1	Symptom burden and specialist palliative care in acute stroke.....	85
2.14.2	Referral rates to specialist palliative care services.....	87
2.14.3	Weekends and end-of-life care.....	88
2.14.4	Information-giving after stroke.....	89
2.15	The LCP and the media.....	91
2.15.1	The Neuberger Report.....	93
2.15.2	Neuberger: responses and implications for this study.....	94
2.16	Summary of key points arising from the literature.....	95
Chapter 3 - Literature pertaining to the methods.....		99
3.1	Research questions.....	99
3.2	Statement of methods.....	99
3.3	The research approach.....	100
3.4	Use of quantitative methods in this study.....	101
3.5	Use of qualitative methods in this study.....	101
3.6	Justification for using mixed methods in this study.....	103
3.6.1	Integrating mixed methods.....	104
3.6.2	Summary of the research approach.....	106
3.7	Challenges in end-of-life data collection.....	107
3.8	Using multiple data collection sites.....	107
3.9	Quantitative element of the study.....	107
3.9.1	Quantitative design.....	108
3.9.2	Quantitative data source.....	108

3.9.3	Quantitative data in a mixed methods study – a practical example	108
3.9.4	Casenote review tool: justification and components.....	109
3.9.5	Casenote review: sampling	110
3.9.6	Quantitative data analysis	112
3.10	Qualitative element of the study	113
3.10.1	Qualitative framework	113
3.10.2	Qualitative data collection.....	119
3.10.3	Qualitative sampling	127
3.10.4	Questionnaire use in interviews	132
3.11	Ensuring rigour in the study.....	133
3.11.1	Rigour in the quantitative study component	134
3.11.2	Rigour in the qualitative study component	135
3.12	Ethical issues.....	139
3.12.1	Beneficence	139
3.12.2	Non-maleficence	140
3.12.3	Respect for autonomy	142
3.12.4	Justice.....	144
3.12.5	Effect on the researcher.....	144
Chapter 4 – Casenote review.....		146
4.1	Study background.....	146
4.1.1	Study sites	146
4.1.2	The LCP and study sites.....	148
4.1.3	Funding	148
4.1.4	Pre-study visits	148
4.1.5	Ethics committee and other governance approvals.....	148
4.1.6	Study adoption	150
4.2	Aims of the casenote review	150
4.3	Research questions	151
4.4	Design.....	152
4.5	Justification for sample size	152
4.6	Access.....	153
4.7	Data collection.....	153
4.7.1	Relationship with existing clinical audits	154
4.7.2	Data collection tool	154
4.7.3	Pilot work.....	155
4.7.4	Issues arising from piloting the casenote review tool	155

4.8	Data handling and storage	157
4.9	Data entry	157
4.9.1	Coding	157
4.9.2	Generating Charlson Comorbidity Index scores	158
4.9.3	Missing data	158
4.10	Data analysis	158
4.10.1	Statistical analysis	158
4.11	Results.....	160
4.12	Differences between LCP and non-LCP groups (Research question 1).....	161
4.12.1	Patient characteristics.....	161
4.12.2	Differences between patient groups: univariate analysis	163
4.12.3	Differences between patient groups: multivariate analysis.....	164
4.13	Clinical decision-making (Research question 2a)	165
4.13.1	Recognising dying and indications for LCP use	165
4.13.2	Recognising dying where LCP was not used	166
4.13.3	Exploring patterns of LCP use	166
4.14	Experiences of LCP use (Research question 2b): Differences between LCP and non-LCP patients.....	169
4.14.1	Care aims, limitations and withholding or withdrawing treatment.....	170
4.14.2	Timing of CPR decisions	171
4.14.3	Enteral feeding	172
4.14.4	Symptom assessment	173
4.14.5	Communicating with primary care.....	175
4.14.6	Communicating with patients and families.....	175
4.14.7	Care relating to religious needs.....	176
4.14.8	Care after death	176
4.15	Answering the research questions.....	177
4.16	Key points for the discussion chapter	178
Chapter 5 – Interviews		179
5.1	Introduction	179
5.2	Aims of the interviews	179
5.3	Research questions	180
5.4	Study sites and ethics approvals	180
5.5	Sample: nature and size	181
5.6	Sampling and recruiting bereaved relatives	181
5.6.1	Inclusion criteria.....	181
5.6.2	Exclusion criteria	181

5.6.3	Access and gatekeepers.....	181
5.6.4	Recruiting bereaved relatives.....	182
5.6.5	Purposive sampling with bereaved relatives.....	183
5.7	Sampling and recruiting healthcare professionals.....	183
5.7.1	Inclusion criteria.....	183
5.7.2	Exclusion criteria	183
5.7.3	Recruiting healthcare professionals	184
5.8	Theoretical sampling	185
5.9	Supporting the recruitment strategy	186
5.9.1	Presence of the researcher as a factor in recruitment.....	187
5.10	Data collection tools	187
5.10.1	Developing the interview guides.....	187
5.10.2	Piloting	188
5.10.3	VOICES II survey tool.....	188
5.10.4	Iterative modifications to healthcare professional interview schedule	188
5.11	Preparing for data collection.....	189
5.12	Supporting the researcher	190
5.13	Data collection: timing.....	190
5.13.1	Timing of contact with relatives in Site D	190
5.14	Presence of the researcher on stroke units as a factor in data collection	190
5.15	Interviews.....	191
5.15.1	All interviews: Informed consent.....	191
5.15.2	Interviews with bereaved relatives.....	191
5.15.3	Interviews with healthcare professionals	192
5.15.4	Supporting participants	193
5.15.5	Field notes	193
5.15.6	Post-interview contact with participants	194
5.16	Data storage	194
5.17	Coding and analysis	195
5.17.1	Underpinning approach.....	195
5.17.2	Transcription	195
5.17.3	Reading and field notes	196
5.17.4	Initial coding	196
5.17.5	Focused coding	197
5.17.6	Second reviewer and coding	199
5.17.7	Axial coding	200

5.17.8	Organising categories and themes using NVivo	203
5.17.9	Coding journal.....	205
5.17.10	Using memos	206
5.17.11	Achieving data and theoretical saturation	208
5.17.12	Member checking	208
5.17.13	Data entry and analysis of VOICES II survey data	209
5.18	Recruitment.....	210
5.18.1	Characteristics of respondents.....	211
5.18.2	Support required by interview participants	212
5.18.3	Influence of the researcher	213
5.19	Description of the data	213
5.19.1	Data volume and distribution among participants	213
5.19.2	Thick description of the study background.....	215
5.20	Thematic findings	220
5.21	Difficulty and uncertainty	221
5.22	Care quality.....	224
5.23	Active families	228
5.24	Deciding is “a series of crucial steps”	230
5.25	Prolonged dying	245
5.26	“Pro-active” information-giving	253
5.27	Wondering about home or hospice care	255
5.28	Answering the research questions: thematic data	258
5.29	VOICES II findings	259
5.29.1	Care during last hospital admission	260
5.29.2	Care received in the last three days of life	261
5.29.3	Circumstances surrounding the death	262
5.30	Answering the research questions: VOICES II data.....	263
5.31	Key points for the discussion chapter	264
Chapter 6 – Discussion		266
6.1	Introduction	266
6.2	Education and clinical infrastructure	267
6.3	Answering the research questions	268
6.3.1	Clinical and demographic differences between LCP / non-LCP groups	268
6.3.2	Family and healthcare professional perceptions	269
6.3.3	The clinical decision to use the LCP	270
6.3.4	The experience of end-of-life care pathway use for stroke patients, families and the multidisciplinary team	276

6.3.5	Outcome for stroke patients on an end-of-life care pathway transferred from a stroke unit to another care facility	283
6.4	Contribution to knowledge	285
6.5	Methodological issues	286
6.5.1	Alternative data collection methods.....	286
6.5.2	Reliability of casenote data	287
6.5.3	Using the VOICES II tool	287
6.5.4	The use of grounded theory.....	288
6.5.5	Using and integrating mixed methods.....	289
6.6	Rigour and trustworthiness.....	290
6.6.1	Quantitative data	290
6.6.2	Qualitative data	290
6.6.3	Ethical aspects of study conduct	292
6.7	Reflections on the research process.....	293
6.8	Study limitations.....	295
6.8.1	Casenote review	295
6.8.2	Interviews	295
Chapter 7	– Conclusion and recommendations.....	299
7.1	Introduction	299
7.2	Findings and contribution to knowledge	299
7.3	Recommendations for clinical practice	300
7.4	Recommendations for health care policy	301
7.5	Recommendations for education	302
7.6	Recommendations for further research	302
References	304
Appendices	345

List of tables

Table 2-1	Topics and keywords used in searches.....	28
Table 2-2	Variations in 30 day case fatality rates among stroke clinical subtypes. Adapted from Bamford et al., (1990b, 1991).....	58
Table 3-1	Terms for a naturalist epistemology of trustworthiness, as proposed by Lincoln and Guba (1985)	134
Table 4-1	Profile of study sites at study commencement	147
Table 4-2	Cross tabulation of LCP use, by study site	159
Table 4-3	Frequencies and distributions of key demographic and clinical characteristics, by sex.....	162
Table 4-4	Five of the Six Simple Variables (Counsell et al., 2002), by sex	163
Table 4-5	LCP use cross-tabulated with demographic and clinical variables	164
Table 4-6	Frequency and type of recorded clinical reasons to consider LCP use.....	165
Table 4-7	Frequency and type of recorded clinical reasons to consider LCP use for non- LCP patients	166
Table 4-8	Decisions to limit clinical treatments: cross-tabulation of LCP versus non- LCP groups	170
Table 4-9	Documented decision to withdraw treatments or investigations: cross- tabulation of LCP versus non-LCP groups	171
Table 4-10	Time in days from hospital admission to formal recording of DNACPR decision	172
Table 4-11	Clinical decision-making on enteral feeding: cross tabulation of casenote variables in LCP or non-LCP casenotes	173
Table 4-12	Frequency of documented symptoms in patients with and without LCP-based care.	174
Table 4-13	Cross-tabulated frequency of PRN prescribing in casenotes with and without the LCP	175
Table 5-1	Section of transcript showing examples of initial line-by-line coding and in vivo codes (shown in italics).....	197
Table 5-2	Example excerpt from interview transcript showing how initial line-by-line coding labels were condensed into categories	199

Table 5-3	Example of data coded under a theme, showing how focused coding categories were grouped into themes	201
Table 5-4	Extract from matrix - examples of relatives' reports of duration of dying process and related reports of discomfort with that duration of dying	203
Table 5-5	Numbers of invitations to participate, response rates, attrition following recruitment and final interview totals, by participant group	210
Table 5-6	Demographic characteristics of participating relatives, relationship to patients, and interview venues	211
Table 5-7	Demographic and educational characteristics of healthcare professionals ..	212
Table 5-8	Total interview hours and volume of data generated, by study site	214
Table 5-9	Spread of participants across study sites, and totals in each site, by participant category	214
Table 5-10	Total hours spent interviewing and volume of data generated, by participant group	215
Table 5-11	Frequency of relatives' reports of responsibility for clinical decisions, with supporting quotes	241
Table 5-12	Deciding clinical issues: Illustrative quotes of reported level of involvement in decision-making and associated satisfaction with decisions.....	243
Table 5-13	Prolonged dying and presence or absence of distress over prolonged dying, charted in relation to expectations.....	251
Table 5-14	Responses to VOICES II questions "Overall, do you feel that care from doctors/nurses in the hospital was..." [17 respondents]	261

List of figures

Figure 2-1	Flow chart showing numbers of search results and screening process	30
Figure 3-1	Convergent parallel mixed methods design, adapted from Creswell and Plano Clark (2007)	106
Figure 4-1	Diagram showing the bodies from which approvals were required for the casenote review and interviews	149
Figure 4-2	Histogram showing median time of day LCP begun (all four study sites) ..	167
Figure 4-3	Frequency of decisions to use LCP, by weekday and study site	168
Figure 4-4	Bar chart showing median LCP duration against frequency of record in casenotes (n=59)	169
Figure 5-1	Flowchart showing the sequence of decision-making commonly reported by participants as culminating in the use or non-use of the LCP.....	233
Figure 5-2	Histogram showing frequency of relatives' (n=17) reports of discomfort associated with duration of LCP use	247

List of text boxes

Box 5-1:	Extract from field note on the interview with Relative 7	194
Box 5-2:	Screenshot showing examples of free nodes created during the coding process	204
Box 5-3:	Screenshot showing the developing tree node and related child nodes for the ‘Active families’ theme	205
Box 5-4:	Example of a coding journal entry recording the creation of a new coding category	205
Box 5-5:	Extract from coding memo on the theme “Prolonged dying”	207
Box 5-6:	Field note made on 21st June 2012, reflecting on a newspaper article published the previous day	217

List of appendices

Appendix 1	Typical documentation for the LCP (version 11)	344
Appendix 2	Views of Informal Carers: Evaluation of Services tool.....	354
Appendix 3	Approval letter from NHS Research Ethics Committee.....	368
Appendix 4	Researcher letter of response to Ethics committee	372
Appendix 5	Final approval letter from Ethics committee	374
Appendix 6	Letters granting NHS Research & Development approvals	376
Appendix 7	Letter of advice from Ethics Committee scientific officer	382
Appendix 8	Approval letter from University Ethics Committee	383
Appendix 9	Approvals from Caldicott data guardians in each health board.....	384
Appendix 10	Data extraction tool for casenote review	391
Appendix 11	Record of consent from relatives to be contacted	395
Appendix 12	Letter of invitation to bereaved relatives	396
Appendix 13	Participant Information Sheet for bereaved relatives	397
Appendix 14	Consent form: relatives	400
Appendix 15	Letter of invitation to healthcare professionals	401
Appendix 16	Participant Information Sheet for healthcare	402
Appendix 17	Consent form for healthcare professionals	405
Appendix 18	New version record of verbal consent for family to be contacted	406
Appendix 19	Staff information poster for display in duty rooms	407
Appendix 20	Ethics committee approval letter for minor amendment	408
Appendix 21	Initial guide for interviews with bereaved relatives	409
Appendix 22	Initial guide for interviews with healthcare professionals	410
Appendix 23	Final guide for interviews with bereaved relatives	412
Appendix 24	Final guide for interviews with healthcare	413
Appendix 25	Permission to use VOICES II questionnaire	415
Appendix 26	Photo of an OSOP (One Sheet of Paper) analysis	416
Appendix 27	Lay summary of the study	417

Thesis synopsis

This thesis begins with a brief outline of personal motivations for undertaking the study and then a statement of the research aims.

In Chapter Two, an integrative literature review is presented. The end-of-life care pathway used in the study stroke units i.e. the Liverpool Care Pathway (LCP) is defined and discussed. The effectiveness of end-of-life care pathways is reviewed and the background to end-of-life stroke care is described. Literature relating to the recognition of dying, end-of-life decision-making and patient, family and healthcare professionals' experiences of the LCP is evaluated. The relevance of preferences for place of care is discussed and challenges in end-of-life care after stroke are outlined. The chapter concludes with an account of the UK review and subsequent withdrawal of the LCP from clinical practice, and the research questions are articulated.

In Chapter Three, literature pertaining to the selected methods is reviewed. The use of mixed methods and a modified grounded theory approach are discussed, and the qualitative and quantitative study methods justified, including the use of multiple hospital sites. Measures to ensure study rigour are reviewed and strategies to ensure ethical research conduct are also considered.

The original research is presented in Chapters Four and Five. Study sites and approvals are reported in Chapter Four after which the quantitative casenote review is reported. In Chapter Five, the qualitative semistructured interviews and VOICES survey are addressed. Research conduct and findings are detailed in these chapters. Thereafter, key points for discussion are stated in relation to the research questions.

Then, findings from both the quantitative and qualitative study components are integrated for discussion in Chapter Six. The implications of the LCP's withdrawal in the UK are considered in relation to this study. Then the study findings are discussed in relation to the literature and in terms of the research questions. The study's contribution to knowledge is stated before methodological issues, study rigour and trustworthiness and study limitations are discussed.

Finally, conclusions are presented in Chapter Seven, with recommendations for clinical practice, health care policy, education and research.

Acknowledgements

I acknowledge the contributions of multiple individuals and organisations which enabled this research.

First and foremost, sincere thanks to the study participants for giving their time and sharing their stories, thereby making this study possible.

I am indebted to my supervisors Professor Emerita Lorraine N Smith and Professor David J Stott for their rigorous guidance.

Thanks to Chest Heart & Stroke Scotland for study funding, to the Nursing & Health Care School, University of Glasgow and the NHS Greater Glasgow & Clyde Stroke Managed Clinical Network for support with fees, and to the Scottish Stroke Research Network for adopting the study.

Similarly, I thank the study grantholders for helping to co-ordinate data collection at study sites and for their comments on analysis. I am deeply grateful to the ward clerks in each study site who, for reasons of confidentiality, cannot be named but whose help made data collection much easier. I am also grateful to Dr Rachael Fulton MacIsaac of the University of Glasgow for her advice on statistics.

To my colleagues and fellow students in the Nursing & Health Care School, University of Glasgow, I offer my appreciation of your camaraderie and methodology chat. And I thank my friends Karen Krawczyk for personal and professional mentorship and Bonnie McDowell for offering her home as a writing retreat.

Finally, my deepest gratitude goes to my family for their loving support and encouragement, rendered unstintingly over the years. I thank Donald, Beth, Katrine, Mirin and Stella Cowey for their patience and care. I thank my sister Alison Black for her friendship, encouragement and much babysitting. And I thank my Mum, Dr JS Wallace for her continued warm interest and for many useful stroke information links.

I dedicate this thesis to the memory of Iain WKK Wallace, who would have been very pleased.

Declaration

I declare that, except where explicit reference is made to the contribution of others, this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Eileen Stewart Cowey

List of publications

Papers

Cowey E, Smith LN, Stott DJ, McAlpine CH, Mead GE, Barber M and Walters M. (2015) Impact of a clinical pathway on end-of-life care following stroke: a mixed methods study. Palliative Medicine, 29(3), pp. 249-259.

Conference proceedings

Current Issues in Palliative Care 11th National Conference 2016: (Oral presentation) Palliative and end of life care in stroke. Cowey, E

Scottish Stroke Nurse Forum Conference 2014: (Oral presentation) End of life care in acute stroke units. Cowey E, Stott DJ, Walters M, Barber M, McAlpine C, Mead G, Smith LN.

British Association of Stroke Physicians Trainees' Conference 2014: (Oral presentation) End of life care in stroke. Cowey E

UK Stroke Forum Conference 2013: (Oral presentation) Using the Liverpool Care Pathway in acute stroke units: a multi-centre study. Cowey E, Stott DJ, Walters M, Barber M, McAlpine C, Mead G, Smith LN.

13th World Congress of the European Association for Palliative Care 2013: (Poster presentation) Use of the Liverpool Care Pathway in end-of-life care following acute stroke: the role of families. Cowey E, Stott DJ, Walters M, Barber M, McAlpine C, Mead G, Smith LN.

UK Stroke Forum conference 2012: (Poster presentation) What factors influence use of the Liverpool Care Pathway in end of life care following acute stroke? Cowey E, Stott DJ, Walters M, Barber M, McAlpine C, Mead G, Smith LN.

List of abbreviations

The following abbreviations are used in this thesis:

ADL	activities of daily living
ASU	acute stroke unit
CCI	Charlson Comorbidity Index
COPD	chronic obstructive pulmonary disease
CPR	cardiopulmonary resuscitation
DNACPR	do not attempt cardiopulmonary resuscitation
GP	general practitioner
HCP	healthcare professional
ICU	intensive care unit
IQR	interquartile range
LACS	lacunar stroke
LCP	Liverpool Care Pathway
MDT	multidisciplinary team
MORECare	Methods Of Researching End of life Care
NHS	National Health Service
NIHSS	National Institutes of Health Stroke Scale
OCSP	Oxfordshire Community Stroke Project
OSOP	One Sheet of Paper analysis method
PACS	partial anterior circulatory stroke
POCS	posterior circulatory stroke
PRN	<i>pro re nata</i> , or as required
RCT	randomised controlled trial
SALT	speech and language therapist
SPSS	Statistical Package for the Social Sciences
SSRN	Scottish Stroke Research Network
SSV	Six Simple Variables
SUPPORT	Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments
TACS	total anterior circulatory stroke
VOICES	Views of Informal Carers Evaluation of Services
VOICES II	Views of Informal Carers Evaluation of Services stroke-specific version
WHO	World Health Organization
WTE	whole time equivalent

Chapter 1 - Introduction

1.1 Personal motivation for conducting the study

In 2008 the Scottish government issued guidance on the use of end-of-life care pathways. Care pathways are standardised care plans, designed to support the care of patients with specific clinical conditions and which identify all the care that patients with the relevant condition should receive from the beginning to the conclusion of the care episode (Campbell, Hotchkiss, Bradshaw, & Porteous, 1998). The Liverpool Care Pathway (LCP) was the best known, and most widely used, example of such a plan for end-of-life care. The Scottish guidance was that end-of-life care pathways such as the LCP or an equivalent should be used in all care settings (The Scottish Government, 2008).

This study was conceived two years later, during the development of a best practice statement on end-of-life care following acute stroke. I managed the project and carried out the evidence review underpinning the work. Research evidence in the area was limited but the working group was able to extrapolate from it to produce a statement of best practice (NHS Quality Improvement Scotland and University of Glasgow, 2010). My interest in end-of-life care pathways was raised when working group members described a paradox: while government advice led them to use these pathways, there was scant guidance as to when such use should begin. The resultant best practice statement highlighted the difficulty of recognising dying in acute stroke and consequently of judging when to implement an end-of-life care pathway.

Around that time suggestions were also emerging in the UK media that some families were being excluded from LCP-related decision-making for their relatives (Devlin, 2009). Additionally, the evidence base for the LCP's effectiveness was weak. The academic literature then consisted of low level evidence insufficient for Cochrane review (Chan and Webster, 2010), editorials debating how best to evaluate the LCP as a complex intervention (Ellershaw, 2007) and letters to peer-reviewed journals criticising the evidence base for the LCP (Shah, 2005a; Treloar, 2008). Thus the clinical uncertainty around recognising dying, coupled with concerns about family involvement in decision-making and criticism of the LCP's evidence base distilled into the research topic for this thesis.

Several years later, near the end of this study, the Department of Health instigated an England-wide review of the LCP, with a similar aim i.e. to explore how the LCP was used by healthcare professionals and to understand patient and family experiences of LCP use.

The review (Neuberger et al., 2013) was instituted following events that occurred during the lifespan of this study and which made the LCP so publicly and politically controversial that it was withdrawn. These events are discussed more fully in the literature review which follows. Suffice to say that this study became a unique opportunity to examine the use of the LCP in stroke care.

In summary, I was interested first in the apparent challenges highlighted by the best practice statement work, namely those of recognising dying and instituting end-of-life care after acute stroke. I knew these were points of difficulty to explore. Further, the experiences of patients, families and healthcare professionals merited investigation.

1.2 Study aims

The goal of the research was to evaluate how an end-of-life care pathway i.e. the LCP, was used in acute stroke care, a specialty with distinctive clinical challenges such as sudden illness onset, dysphagia, aphasia, cognitive impairment and uncertain outcome. Therefore the aims of the study were:

- To describe characteristics of stroke patients on an end-of-life care pathway and characteristics of stroke patients who die but who are not on an end-of-life care pathway
- To explore the clinical decision-making involved in placing patients on an end-of-life care pathway
- To explore the role of families in clinical decision-making
- To examine experiences of end-of-life care pathway use for stroke patients, their relatives and the multi-disciplinary health care team

- To explore preferred place of care for patients on end-of-life care pathways in acute stroke units

In the next chapter, the literature review strategy and findings are presented.

Chapter 2 - Literature Review

In this chapter, a review of the relevant literature is presented. The purpose of a literature review is to explore the existing knowledge on a given topic (Burns and Grove, 2009), to justify further research and to help refine research questions (Coughlan, Cronin and Ryan, 2013). Therefore this review is used to examine evidence regarding the effectiveness of end-of-life care pathways and their use in stroke care. Further, the review includes research on decision-making related to end-of-life care pathways, and studies of patient and family experiences of end-of-life care pathways, both generally and in stroke contexts. Whittemore and Knafl (2005) suggest that integrative reviews are suitable for combining a range of experimental and observational evidence, thereby enriching understanding of complex clinical topics. Accordingly, this review integrates findings from qualitative and quantitative studies i.e. observational and randomised controlled trials.

2.1 Outline of the literature review

The review begins with a definition of key terms and a report of the strategy which was used to identify literature. The LCP is presented and discussed in some detail to set the scene for the reader. Thereafter the study background is reported, identifying the scale of end-of-care needs after stroke and the UK and Scottish policies and guidance surrounding care delivery. The quality of UK and Scottish end-of-life care is discussed and social and professional attitudes to death and dying are then reviewed, before relevant theoretical concepts in end-of-life care are considered.

The review then addresses literature relevant to the research aims. Studies exploring the challenge of recognising dying are assessed, and the implications for end-of-life stroke care are considered. Literature on shared clinical decision-making is examined and evidence of the role of patients, families and healthcare professionals in end-of-life decision making is appraised. Evidence of patient, family and healthcare professionals' experiences of LCP use is examined with reference to stroke settings and the relevance of place of care is considered. Thereafter literature relating to specialist palliative care services, weekend end-of-life care and information-giving is discussed. Finally, the demise of the LCP is reported and the implications for this study are evaluated.

The review demonstrates gaps in the evidence base underpinning end-of-life stroke care and concludes by articulating the research questions. The review also identifies research methods suitable for this study, which aimed to address the dearth of literature in the field.

2.2 Key definitions

Throughout this thesis, the term ‘end-of-life’ refers to the last hours or days of life. This is consistent with the UK General Medical Council (2010) definition where although ‘end-of-life’ may be used broadly in relation to the final 12 months of life, it also applies where patients are expected to die imminently:

“... Patients are ‘approaching the end-of-life’ when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with... life-threatening acute conditions caused by sudden catastrophic events.” (General Medical Council, 2010: 8)

According to the Scottish Partnership for Palliative Care (2007), end-of-life care is a component of broader palliative care and begins after a diagnosis that a patient has entered the dying process. This review therefore focuses on end-of-life care, rather than palliative care, in acute stroke.

For the purpose of this study and in line with Warlow et al. (2008), stroke is defined as:

“A clinical syndrome characterized by an acute loss of focal cerebral function with symptoms lasting more than 24h or leading to death, and which is thought to be due to either spontaneous haemorrhage into the brain substance (haemorrhagic stroke) or inadequate cerebral blood supply to a part of the brain (ischaemic stroke) as a result of low blood flow, thrombosis or embolism...” (Warlow et al., 2008: 40)

Warlow et al. (2008) also state that the course of illness after stroke is fluctuant and unpredictable and its outcome is uncertain (Warlow et al., 2008).

The literature shows a range of definitions for the term ‘acute stroke.’ In a study linking mortality data with routine hospital data, Goldacre, Roberts and Griffith (2004) defined the acute phase as the first 30 days of admission after stroke. Similarly, in a systematic review of the prevalence of depression in acute stroke, Kouwenhoven, Kirkevold, Engedal, & Kim

(2011: 539) defined the acute phase “within the first month” after stroke. However, in a phenomenological study of depression in the acute phase of stroke, Kouwenhoven, Kirkevold, Engedal, & Kim (2012) used a wider definition, collecting data four to seven weeks post-stroke. In contrast, a shorter time period was used in two longitudinal cohort studies investigated associations between fatigue (Lerdal and Gay, 2013) or demographic and clinical variables (Eriksen, Gay and Lerdal, 2016) in the acute post-stroke phase and long term outcomes. The studies defined the acute phase as occurring either within the first two weeks (Lerdal and Gay, 2013) or the first 15 days (Eriksen, Gay and Lerdal, 2016) post-stroke.

Definitions of ‘acute stroke care’ also vary, according to a systematic review of stroke unit effectiveness that included studies from 14 countries (Stroke Unit Trialists’ Collaboration, 2013). The Collaboration reported that internationally, acute stroke units (ASUs) generally provide care immediately after stroke and for up to seven days. Acute stroke care can also be provided in comprehensive units that integrate acute and rehabilitative care immediately post-stroke and for a minimum of several weeks thereafter if needed.

Hence for the purposes of this study the term ‘acute stroke’ includes the period from stroke onset up to one or two months post-stroke. The term ‘acute stroke unit’ includes stroke units providing care within the first seven days, and comprehensive units which provide acute stroke care for at least several weeks post stroke.

2.3 Search strategy

Searches were run between August 2011 and January 2012 using the following databases: All Evidence Based Medicine Reviews, Allied and Complementary Medicine Database (AMED), British Nursing Index, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Library, Embase, Google Scholar, International Bibliography of the Social Sciences (IBSS), Medline, ProQuest Dissertations and Theses (USA & Canada and UK & Ireland), PsycBite, PsycInfo, Scopus, and Web of Science. The keywords are shown in Table 2-1. Keywords were augmented using synonyms, free text terms and US National Library of Medicine Subject Headings specific to each database. The keywords were grouped into topics for searching and these are also shown in Table 2-1. Searches

were limited to publications from 1997 onwards, since 1997 was the year of LCP publication. Reference lists of relevant retrieved papers were searched for earlier landmark studies.

Ongoing trial registers (www.trialscentral.org, www.controlled-trials.com, www.who.int/trialsearch) were searched. Government and professional health organisation websites were also searched for grey literature. Results were exported to Mendeley reference management software for de-duping and screening.

Table 2-1 Topics and keywords used in searches

Topic group	Keywords
Families	Family, interpersonal relations, caregivers, friends, siblings, parents, spouses, proxy
Multi-disciplinary team	Patient care team, health personnel, interdisciplinary, multidisciplinary, nurses, medical staff, allied health personnel
Decision-making	Decision making, judgement, thinking, professional autonomy, problem solving
Stroke	Stroke, cerebrovascular accident
End-of-life	Dying, end of life, end-of-life, hospices, palliative care, terminal care, terminally ill
Care pathways	Care map, care path, care pathway, care plan, clinical practice guideline, clinical, compliance, critical path, critical pathways, end of life pathway, guideline adherence, guideline, health planning guidelines, integrated care pathway, LCP, Liverpool Care Pathway, nursing protocol, policy, protocol,
Research methods	Comparative study, controlled clinical trial, experiment, evaluation studies, intervention studies, mixed methods research, nursing research, qualitative research, post-test, pre-test, random allocation, randomized controlled trial

Email alerts were established from the initial searches to identify new papers as they were published throughout the lifespan of the project. Alerts were ended on 31st March 2016 to enable completion of the thesis.

Papers identified from searches were included for review if they were published in English, referred to a research study in adult humans and addressed either decision-making and care pathways, care pathways and families, end-of-life decision-making and family proxies, end-of-life care and stroke, or end-of-life care pathways and the multi-disciplinary team.

There were few studies of end-of-life care pathways in stroke settings hence papers relating to any hospital setting were included.

All electronic search results were combined and screened by title and abstract (see Figure 2-1). Full-text articles of potentially relevant papers were retrieved for further screening and papers not meeting inclusion criteria were excluded.

2.3.1 Search results

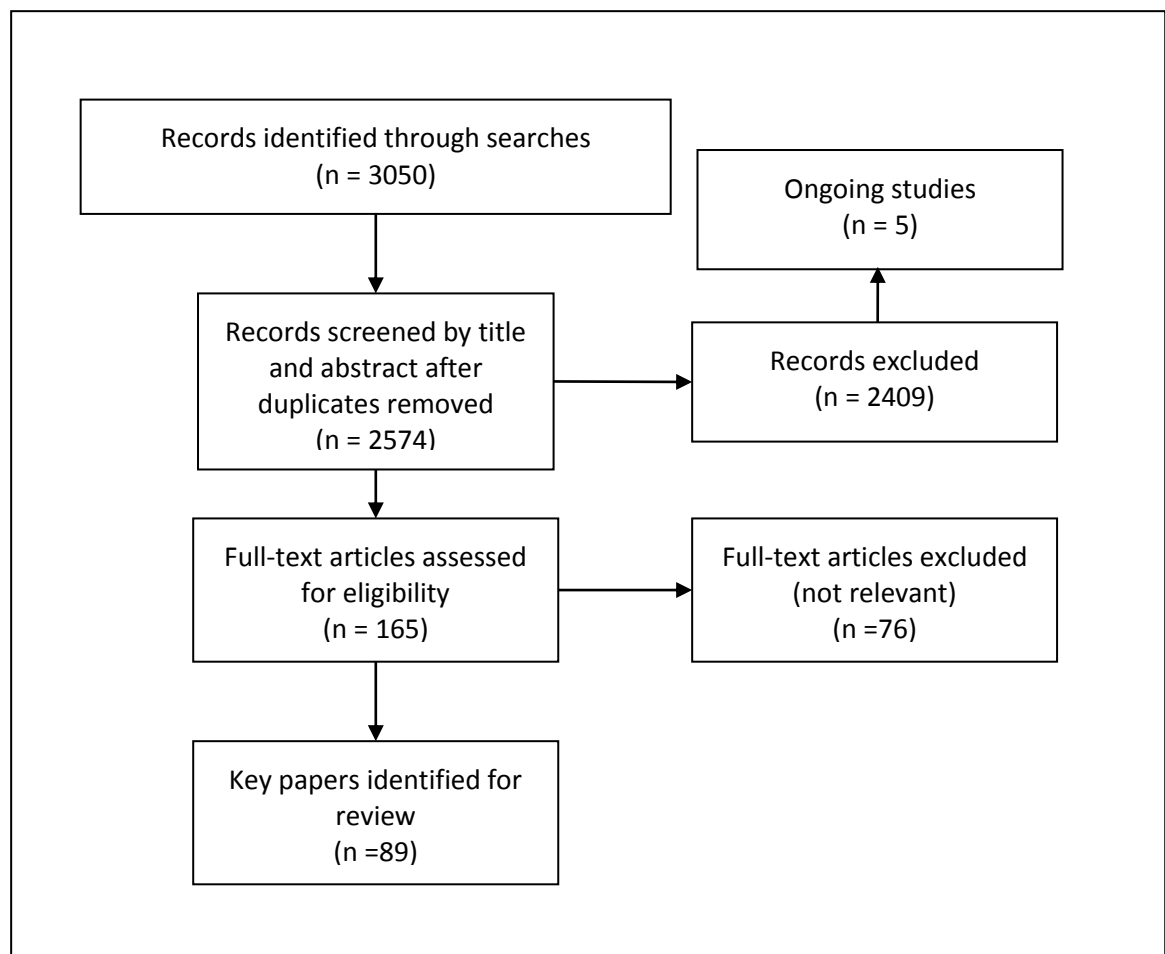
Five ongoing studies were identified. One was a cluster RCT (Costantini, 2010), two used qualitative mixed methods (Ellershaw, Haycox and Perkins, 2010; Dalkin, Jones, Lhussier and Cunningham, 2012) and two were quasi-experimental studies (Brännström, 2011; Costantini, 2011). The ongoing studies were included in continuing online search alerts.

The volume of literature identified in the initial searches was large and over the time of the PhD there were many further publications on end-of-life care and on the LCP. Initially, using the inclusion criteria (see 2.3) narrowed the focus to papers that related to the research aims. Later, once the initial literature review was complete and the research questions clarified, new publications were added to the review only if they addressed the research questions. This ensured the volume of literature remained manageable.

From the original searches in 2011-2012, 89 relevant publications were identified (Figure 2-1). Of these, there were 57 papers in peer-reviewed journals, 20 reports, policy or clinical guidance documents, nine books or book chapters and two newspaper articles. Throughout the PhD period thereafter, online alerts yielded another 78 relevant papers, including research studies, public reports and news media reports covering the public debate on the LCP.

Papers are now grouped by topic for review.

Figure 2-1 Flow chart showing numbers of search results and screening process. Adapted from Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart (Moher, Liberati, Tetzlaff and Altman, 2009)



2.4 Defining the LCP

Given this study's focus on the Liverpool Care Pathway (LCP), the LCP's development, content, popularity and evidence base is now described in some detail. Evidence relating to the LCP's clinical use is integrated throughout the review. The demise of the LCP, including the related media storm and the influential Neuberger review are reported at the end of the literature review, so the reader has an opportunity to form their own view on the relative merits of the LCP.

The LCP was developed in the UK by Ellershaw et al. (1997), using the concept of integrated care pathways proposed by Kitchiner and Bundred (1996). According to Ellershaw et al. (1997), care pathways evolved from a quality improvement and outcomes-driven approach to care that was common in the business management models of US

healthcare. Using such an approach, Ellershaw et al. (1997) argued, helped healthcare organisations ensure that measurable care goals were met and care quality could be assured. According to Ellershaw et al. (1997), the LCP was designed to take the hospice model of care into acute hospital settings using a quality improvement and outcomes-driven approach.

Ellershaw et al. (1997) defined a care pathway as:

“...Providing a flowsheet that outlines the expected and realistic course of a patient’s care. Each episode can be described, tracked and monitored to ensure that intermediate and final outcomes are within an accepted range of quality. A pathway specifies an agreed plan of care by contributing professionals, including members of the core professional team and those who are on the periphery.” (Ellershaw et al., 1997: 203)

Ellershaw et al. (1997) reported that the LCP was developed in one UK hospital service by a multidisciplinary committee that included palliative care specialists. The group operated by consensus, reviewing literature on end-of-life care to identify relevant care interventions and outcomes. The size of the group and the quality or volume of literature reviewed was not reported. The group then consulted community and hospice palliative clinicians to develop care pathway documentation. The documentation listed goals of care and gave instructions that directed care of the dying. Associated information leaflets for families were developed.

Ellershaw and colleagues (Vanhaecht et al., 2011) later defined care pathways as complex interventions i.e. interventions that integrated evidence-based care with team, patient and family communication, co-ordinated care processes, documentation and monitoring, and resource allocation. According to Ellershaw and Wilkinson (2011) the LCP was a set of multidisciplinary documents to replace all other records of care and a recent version is shown in Appendix 1.

The documents supported:

- Initial patient assessment, on-going assessment and management, care after death
- Assessment and care of physical, psychological, social and spiritual needs of patients and families

- Clinical and organisational governance by providing documents in an auditable format.

The LCP enabled clear recording of irreversible clinical deterioration, decisions not to initiate cardiopulmonary resuscitation (CPR) or to withdraw treatments such as clinically assisted nutrition or antibiotics, and prompted hospital staff to communicate with families and the primary care sector. Anticipatory prescribing protocols for symptom management were provided. Tick boxes were used to record achievement or variance from pre-defined goals of care on a four-hourly basis. The documents directed that the full multidisciplinary team (MDT) reassess the patient every three days or at any sign of clinical improvement. The LCP could be discontinued if improvement occurred.

Versions of the LCP before the final Version 12 included a four-point checklist to help healthcare professionals identify imminent death. These indicators were: patients being bedbound, semi-comatose, only able to take sips of fluid and unable to swallow tablets (Ellershaw and Wilkinson, 2003). The criteria were criticised as lacking a scientific evidence base (Domeisen et al., 2011). The points were omitted from Version 12, which gave no specific instructions but directed clinicians to make a holistic multidisciplinary assessment to reach a diagnosis. Nevertheless, Version 11 remained in use in many clinical areas, including in the stroke units reported in this thesis, thus the use of the four criteria persisted.

2.5 Evaluating the LCP

According to Murphy and McGlinchey (2011) a system of audit was established to monitor LCP use in clinical practice across England. Known as the National Care of the Dying Audit - Hospitals, the audit was supported by the UK Department of Health, the Marie Curie Palliative Care Institute Liverpool and the Royal College of Physicians. The first and second rounds of the audit were carried out in 2006 and 2008 (Marie Curie Palliative Care Institute Liverpool and Royal College of Physicians, 2007, 2009). A third round was undertaken in 2011 (Marie Curie Palliative Care Institute Liverpool and Royal College of Physicians, 2011) and a fourth in 2014 following the withdrawal of the LCP from UK clinical practice (Royal College of Physicians, 2014).

In its first three rounds the scope of the National Care of the Dying Audit was limited to patient care that was supported by the LCP. Therefore as the Royal College of Physicians (2014) reported, the fourth round of audit was the first to scrutinise care given to all patients who died in hospital. Consequently, the first three rounds of audit may have excluded more than half the potential sample because there was evidence that end-of-life care pathways were not used universally for patients dying in acute hospitals. Pugh et al. (2010) reported that their casenote audit of all deaths (n=400) in an English National Health Service (NHS) hospital trust over a three-month period showed the LCP was used in 39% of cases audited. Thus Rounds One to Three of the National Care of the Dying Audit could be seen as an audit of LCP use, rather than an audit of care given to all dying patients. While National Care of the Dying Audit findings indicated some high standards of care, for example Round 3 found 91% (n=5610) of casenotes showed anticipatory prescribing for common end-of-life symptoms (Marie Curie Palliative Care Institute Liverpool and Royal College of Physicians, 2011), the findings were not representative of the general population and should therefore be treated with caution. Further, the audit did not address end-of-life care across the UK, reflecting only the care provided in hospitals in England.

In relation to stroke, Round Three of the National Care of the Dying Audit reported LCP use for 7,058 patients in England, 12% (n=819) of whom had a primary diagnosis of stroke (Marie Curie Palliative Care Institute Liverpool and Royal College of Physicians, 2011). The LCP was typically used for patients dying from non-malignant diseases for a longer time (31 hours before death) than for patients dying from cancer (27 hours). Whether these figures are means or medians was not reported. An interquartile range (IQR) of 11-72 hours was reported for LCP duration in cancer patients but no IQR was reported for patients dying of non-malignant conditions.

2.6 The rise of the LCP

Rapid and widespread adoption of the LCP ensued; by 2001 the LCP was granted beacon status by the UK NHS (Ellershaw and Ward, 2003) and shortly afterwards recommended for use in end-of-life cancer care (National Institute For Clinical Excellence, 2004). Before the UK media debate of 2012-2013 Murphy (2011) reported that the LCP was used in 21

countries world-wide. According to Smeding, Bolger and Ellershaw (2011) LCP use spread to Argentina, Austria, Germany, India, Italy, the Netherlands, New Zealand, Norway, Slovenia, Sweden and Switzerland. Other end-of-life care pathways existed but these largely evolved from the Liverpool Care Pathway (Chan and Webster, 2013).

Because of their origins in hospice care, Ellershaw (2007) suggested that end-of-life care pathways tended to reflect the aims of cancer care. Although the Liverpool Care Pathway was eventually modified for patients dying from renal disease and heart failure (Department of Health, 2008), for use in A&E departments (Paterson et al., 2009), intensive care units (Walker and Read, 2010) and burns units (Hemington-Gorse et al., 2011) it was never adapted for stroke care, despite the significant mortality associated with stroke in the UK and internationally (see 2.8.1).

2.7 The evidence base for end-of-life care pathway effectiveness

In this section, the evidence base for end-of-life care pathways is considered. This study was designed and data collection commenced in 2010-2011 when only one systematic review (Chan and Webster, 2010) and observational studies had been published on end-of-life care pathways. During 2011-2013 other reviews were published consistent with the findings of the initial literature review for this study, thereby confirming this study's research questions. The reviews are integrated for consideration here.

Before the LCP was developed, Pearson, Goulart-Fisher and Lee (1995) published a critical account of general care pathway use in the United States. They expressed concerns about the rapid implementation of care pathways without supporting evidence from controlled trials. This concern was repeated in relation to end-of-life care pathways by Shah (2005b), who suggested that rigorous testing of LCP effectiveness had been precluded by its rapid shift from development to widespread implementation. Shah (2005b) also suggested that since the LCP was not yet implemented in every UK hospital, a randomised cluster trial would still be possible before further rollout occurred.

Ellershaw, Haycox and Perkins (2010) were funded by the UK NHS to undertake a mixed methods comparison of end-of-life care in 24 English intensive care units (ICUs) and nursing homes, half of which were using the LCP. According to their protocol they would

use interviews, observation, case note analysis and economic analysis to compare sites and investigate the impact of the LCP. Searches and alerts for this review did not uncover a final publication relating to this grant so findings were not available for discussion.

In 2011 Phillips, Halcomb and Davidson published an integrative review of qualitative and quantitative evidence on the impact of end-of-life care pathways in acute hospitals and hospices. They searched seven databases to identify primary research studies written in English that evaluated patient or family care which included an end-of-life care pathway. Out of 638 search results 26 studies were identified for review using standardised data extraction and critical appraisal tools. Two reviewers extracted data with input from a third where necessary. The retrieved studies were too heterogeneous for meta-analysis so Phillips, Halcomb and Davidson (2011) undertook a thematic content analysis of the extracted data. The majority of studies identified were from the UK, the US, Netherlands or Australia. There were no randomised controlled trials (RCTs) and the majority of studies had before-and-after observational designs.

Phillips, Halcomb and Davidson (2011) found weak evidence that end-of-life care pathways were of benefit in acute hospitals and hospices. In the qualitative studies, staff reported that pathways improved care and there was retrospective questionnaire evidence that end-of-life care pathways were associated with reduced symptom burden for patients and reduced bereavement levels in relatives. Nevertheless Phillips, Halcomb and Davidson (2011) concluded that the use of end-of-life care pathways was hampered by the weak evidence base, the general cancer care focus of the pathways, the requirement for recognition of dying before pathway use could begin, lack of evidence about indicators of dying and clinicians' educational deficits on recognising dying and using pathways.

The lack of robust evidence was reported again by Chan and Webster (2013) in an updated Cochrane systematic review on the effectiveness of end-of-life care pathways. According to the Cochrane Collaboration (2015), Cochrane reviews are systematic reviews of primary research, recognised internationally as being conducted to rigorous and explicit standards, published electronically and updated regularly. Cochrane reviews examine clinical effectiveness or diagnostic test accuracy and therefore focus on RCTs and controlled trials. The Cochrane Collaboration (2015) suggests that their rigorous methods are preferable to

narrative literature reviews which may draw on limited searches thereby omitting key evidence.

Chan and Webster (2013) updated their 2010 review of trials comparing end-of-life care pathways versus usual care, or trials comparing one end-of-life care pathway against another. The outcomes of interest were the effects of pathway use on symptoms and quality of life, and on relatives and carers. Both reviews were to include RCTs, cluster-RCTs, quasi-randomised and non-randomised controlled trials, conducted in cancer or non-malignant disease groups and relating to any age group or clinical setting. Chan & Webster searched four publications databases, four trials registers and one database of international dissertations and theses, conference proceedings, reference lists of relevant papers, hand-searched journals and they contacted experts. No language limits were set, abstracts were translated where necessary and search terms were tailored to each database. The two authors screened titles and abstracts independently. The full text of potentially relevant papers were retrieved and screened independently, again by both authors.

Chan & Webster (2013) identified 32 studies relevant to their search question, including 28 identified in their original 2010 review. Yet none met the quality criteria for inclusion. Consequently Chan & Webster (2013) concluded there was no strong evidence to support pathway use. Nevertheless they emphasised that none of the studies they scrutinised had identified adverse effects from pathway use and whilst acknowledging the withdrawal of the LCP in the UK, Chan & Webster (2013) suggested there was a lack of data to support that decision. They called for more data to clarify whether the poor care reported by Neuberger et al. (2013) arose from the LCP tool itself or from misuse of the tool. The Neuberger report and its consequences are considered in 2.15.1.

To support the Neuberger investigations, Parry et al. (2013) were commissioned by the NHS National End of Life Care Programme to undertake a rapid evidence review of end-of-life care pathways and associated issues such as recognising dying and communication with families. According to Hemingway and Brereton (2009) rapid evidence reviews are useful in scoping the literature and involve a focused form of systematic review, often carried out over short time periods (2-6 months), where limits of publication age and language are applied. The review by Parry et al. (2013) had a wider scope than Phillips, Halcomb and Davidson (2011) and Chan & Webster (2013) because it also examined

evidence on care pathways in general as well as end-of-life care pathways. Parry et al. (2013) contacted the researcher for information about the study reported here, and this study is listed as on ongoing trial in their review.

Parry et al. (2013) used separate search questions for each area of interest and prioritised systematic reviews over other studies. They scrutinised four systematic reviews, including two Cochrane reviews, of care pathways in general hospitals, stroke care or surgery. They examined a further three systematic reviews including Phillips, Halcomb and Davidson (2011) and Chan & Webster (2013) in relation to end-of-life care pathways, three systematic reviews and two primary research studies relating to recognition of dying and two primary research studies of end-of-life communication between patients, families and staff. They identified widely varying definitions of the term 'care pathway' and found some evidence of care pathway effectiveness in general hospitals and surgical areas i.e. reduced in-hospital complications and improved documentation. Conversely, in stroke care use of an in-hospital care pathway was associated with poorer reported quality of life and patient satisfaction than usual care.

Parry et al. (2013) concluded that because of the diversity of interventions labelled as care pathways, these findings could not be extrapolated to end-of-life care pathways. They found no strong evidence of benefit or harm from end-of-life care pathways and agreed with Phillips, Halcomb and Davidson (2011) that there was moderate evidence from staff and family accounts that using end-of-life care pathways might improve aspects of care such as communication and symptom management. Parry et al. (2013) found weak to moderate evidence that recognising dying is more difficult in non-cancer settings where trajectories were uncertain. There was a dearth of evidence on communication between patients, families and staff in the last hours of life, with most published studies relating to longer term palliative care in cancer settings.

It could be argued that these reviews complemented one another. While Phillips, Halcomb and Davidson (2011) were less stringent regarding study quality, their strategy was more pragmatic than Chan & Webster's (2013). Appraising papers reporting weaker designs, enabled a holistic overview of evidence, affording insight into issues associated with care pathway use. Nevertheless by searching for non-English language papers Chan & Webster's (2013) strategy was more extensive than Phillips, Halcomb and Davidson

(2011), reducing the likelihood that evidence was missed. Although Parry et al. (2013) included few primary studies, this avoided replication since their review came soon after Phillips, Halcomb and Davidson (2011) and Chan & Webster (2013). The review by Parry et al. (2013) had a wider scope than either of the previous reviews since it addressed general care pathways as well as those used in end-of-life care.

Findings from the three reviews have implications for the study reported here because they highlighted issues relating to its research questions. While Chan & Webster (2013) confirmed the lack of rigorous evidence regarding end-of-life care pathway effectiveness, the reviews of observational studies by Phillips, Halcomb and Davidson (2011) and Parry et al. (2013) indicated problems associated with using end-of-life care pathway in practice. These included recognising dying, decision-making and patient and family care experiences. Therefore the review findings confirmed the focus of the research questions for the study reported here. Chan & Webster (2013) also acknowledged that evaluating the LCP in the UK would be impossible thereafter because of its withdrawal across the country. Hence this study was one of the last opportunities to investigate LCP use in a UK setting.

In 2013 Higginson et al. addressed the weak evidence base in many studies of end-of-life care, publishing a statement on the evaluation of complex interventions in end-of-life care. The statement identified key principles of rigour in end-of-life care research, and suggested their use as accepted research standards like Consolidated Standards of Reporting Trials [CONSORT] (Schulz, Altman and Moher, 2010) or STrengthening the Reporting of OBservational studies in Epidemiology [STROBE] (von Elm et al., 2007) reporting guidelines. To produce the guidance, Higginson et al. (2013) used three methods to identify challenges in end-of-life research and how end-of-life studies might best fit with accepted research standards. First three systematic reviews were conducted. Then five topic-specific consultation meetings (140 participants) and online discussions (133 respondents) with experts used nominal group technique to rank and agree key points. Finally two patient/carers workshops (n=19) and one clinicians' workshop (n=12) were used to consider how end-of-life research was conducted and reported. Findings were synthesised to produce the Methods Of Researching End of life Care (MORECare) guidance (Higginson et al., 2013).

The MORECare guidance made multiple recommendations for end-of-life care research. In evaluating complex interventions in end-of-life care, Higginson et al. (2013) recommended that researchers use a range of designs, not just RCTs. These designs should incorporate mixed methods, and should include patients and their families where possible. These recommendations appear consistent with findings from the reviews by Phillips, Halcomb and Davidson (2011) and Parry et al. (2013) where inclusion criteria were less stringent than the Cochrane standards of Chan & Webster (2013), yet the reviews yielded useable information on end-of-life issues.

The research community's response to MORECare was swift. In 2014 the first cluster RCT of LCP effectiveness was published (Costantini et al., 2014b) and showed no apparent effect of the LCP on care quality. Single cancer wards in 16 Italian hospitals were randomly assigned to use LCP (intervention) or continue with usual care (controls). The primary outcome measure was an overall care quality score, measured in face-to-face interviews with relatives two to four months after patients' deaths. After randomisation, 119 relatives in the intervention group and 113 in the control group took part. Medical records were reviewed and General Practitioners (GPs) (n=128 intervention, n=132 control) were also interviewed by telephone about communication with secondary care. There were no significant differences in primary outcome scores between the intervention group and controls (70.5/100 vs 63.0/100, 95%CI -3.6 to 18.7, p=0.186).

In intervention wards, the LCP was used for 4-58% of patients. Hence not all eligible patients may have received the intervention. Further, staff and outcome assessors were unblinded, introducing a risk of ascertainment bias. Several other items of interest emerged from the study. There were significant improvements in some secondary outcomes. For example in the intervention group more relatives reported being treated with respect, dignity and kindness (p=0.042). There was improved control of breathlessness (p=0.026) and higher levels of medication administration for pulmonary secretions (p=0.001) than in the control group. No significant difference was observed in survival time between the LCP group (8 days) and controls (7 days).

In conducting their trial, Costantini et al. (2014b) adhered to the MORECare guidance (Higginson et al., 2013) by involving families in the research and mixing methods to some extent. Yet it could be argued that a stronger mixed methods approach, such as the

inclusion of qualitative interviews or observation might have been helpful in identifying more clearly any benefits of the intervention and why rates of use were very low in some wards.

Chan, Webster and Bowers (2016) updated their Cochrane review (Chan and Webster, 2013), identifying 35 relevant studies of which only one (Costantini et al., 2014b) met the quality criteria for inclusion. Chan, Webster and Bowers (2016) agreed with the findings of this review i.e. that Costantini et al. (2014b) provided weak evidence of LCP effectiveness on a limited number of outcomes in cancer patients.

In summary, repeated systematic reviews have not uncovered rigorous evidence that care pathways, including those aimed at end-of-life care, are effective. Most studies used audit or uncontrolled designs or used historical control groups. Nevertheless the reviews did not uncover evidence of harm associated with care pathway use. To address the weak evidence base, the MORECare guidance recommended that for studies evaluating complex interventions such as the LCP, mixed methods should be used and patients and families included. Therefore in its use of mixed methods and inclusion of family members this study design incorporated two key MORECare recommendations.

2.8 Background to the study

Having defined the LCP and considered its evidence base, the background to the study is now considered. First, the scale of end-of-life care needs after stroke are considered globally and in relation to the UK, before policies and guidance governing end-of-life care in the UK home nations are addressed. Thereafter, the quality of end-of-life care in the UK is considered, and public and professional attitudes to death and dying are discussed. Finally, Glaser and Strauss's seminal work from the 1960s investigating care of the dying in hospital is reviewed, and its relevance to modern end-of-life care evaluated.

2.8.1 Mortality, end-of-life care and stroke

According to the World Health Organization (WHO) (2011a) 57 million people die each year worldwide. The Office for National Statistics (2012a) reported that UK deaths

exceeded half a million (n=552,232) annually, with 53,661 occurring in Scotland. Consequently, end-of-life care exerts considerable pressure on healthcare budgets. The National Audit Office (2008) estimated the cost to the UK NHS for palliative care provision for cancer patients in their final 12 months (27% of total UK deaths) was £1.8 billion. Total costs for non-cancer conditions are unclear. In an independent review for the UK Secretary of State for Health, Hughes-Hallett et al. (2011) reported that reliable data on palliative care costs in England were unavailable.

The WHO estimates that annually 19 million adults globally need end-of-life care, of which the majority (60.28%) die from non-malignant diseases including stroke (Connor et al., 2014). Globally, stroke accounts for around 10% of all deaths (WHO Regional Office for Europe 2012) with around six million stroke deaths annually (Davis and Norrving, 2013). The WHO estimates that in Europe (WHO 2011b) and in the UK (WHO 2013), cerebrovascular disease, i.e. stroke, is the third leading cause of death after ischaemic heart disease and cancer.

According to Kunst, Amiri and Janssen (2011) and Go et al. (2013) improvements in stroke management such as thrombolysis, antithrombotic therapy for secondary prevention and organised stroke unit care have reduced stroke mortality in western Europe and the United States in recent years. Yet although mortality in western Europe is decreasing, Kunst, Amiri and Janssen (2011) also suggest that the ageing of populations is likely to slow the decline in absolute numbers of stroke deaths in the UK and France by 2030 and stroke is likely to remain a frequent cause of death in the elderly.

There is some evidence from the UK that deaths after stroke often occur in the acute phase of stroke and often in hospital. Goldacre, Roberts and Griffith (2004) examined geographic location and timing of adult deaths in the year after index MI or stroke in the Oxford area, by linking hospital records and death registrations. Of the 7,070 deaths in the year after stroke, 4,905 (69.4%) occurred within the first 30 days, and of these 91.9% (4,509) took place during the index hospital admission. Although the study was limited to one geographical area and more recent figures might show reductions in mortality linked to improvements in stroke care, mortality after stroke is still a considerable problem in UK healthcare. The National Audit Office (2010) reported that in England approximately 110,000 strokes were recorded annually and around one in four people having a stroke died

as a result of it. During the data collection period of this study i.e. 2011-2012, the NHS Information Services Division (2012) reported that in Scotland, all age 30-day mortality after acute stroke was 16.9% (n=1,148), rising to 23.6% (n=835) for the over-75s. More recent provisional Scottish figures (Information Services Division Scotland, 2016) indicate that in 2014-15, while all age 30-day stroke mortality has reduced to 15.1% (n=981), it remains higher for over those aged over 75 (30-day mortality 21.4%, n=732). Hence death occurring in the acute phase of stroke remains a substantial clinical issue.

2.8.2 Policy context at the beginning of this study

The majority of adequate palliative care provision is in the developed world i.e. Western Europe, Australia, New Zealand and north America (Economist Intelligence Unit, 2010) although according to the European Association for Palliative Care (2013) relatively few countries have clear policies to define and guide the provision of palliative care.

Nevertheless, when this study began end-of-life care was designated a priority across the UK, with each home nation producing strategies to stimulate improvements for all dying patients, regardless of diagnosis, and advocating the implementation of end-of-life care pathways in all care settings and the provision of education and training for the clinical workforce (The Scottish Government, 2008; Department of Health, 2008; All Wales Palliative Care Planning Group, 2008; Department of Health Social Services and Public Safety, 2010). In its strategy, the Scottish Government (2008) directed that the LCP or an equivalent tool should be implemented in all clinical areas for patients dying from "advanced progressive conditions" (p14) and committed to supporting health boards with implementing the LCP or an equivalent, particularly through the provision of educational support from the organisation NHS Education for Scotland. The Scottish Government document also recommended "flexible" (p36) use of the LCP but without making explicit what the term meant.

In common with the other home nation strategies, the Scottish Government (2008) recommended the use of advance care plans, where patients and carer preferences were discussed in advance of clinical deterioration to guide future care when patients became unable to express preferences. The strategy directed that advance care planning should be

used to elicit patients' preferences regarding their place of care, with the aim of reducing numbers of hospital deaths and facilitating dying at home where it was preferred by patients.

In summary, end-of-life care is a major part of worldwide, UK and Scottish healthcare. When this study began, UK and Scottish Government guidance recommended the use of end-of-life care pathways such as the LCP for patients dying in all clinical areas. Further, guidance stated that patient and carer preferences regarding place of care should be elicited.

During the course of this study, UK end-of-life healthcare policy changed, particularly with regard to end-of-life care pathways. By the time this thesis was approaching completion in 2016, end-of-life care pathways were no longer recommended. Further details are provided and the implications for this study considered in 2.15.2.

2.8.3 Guidance for end-of-life care after stroke

Several key documents are available to guide end-of-life care after stroke in the US (Holloway et al., 2014), the UK (Intercollegiate Stroke Working Party, 2012a) and Scotland (NHS Quality Improvement Scotland and University of Glasgow, 2010). Holloway et al. (2014) developed a US clinical guideline on end-of-life care in stroke from their review of 284 papers, using the American Heart Association Framework to categorise evidence levels and recommendations. They recommended that clinicians acknowledge uncertainty with families and indicate specific pointers of improvement or deterioration, that patient proxies should be given access to bereavement services and that stroke healthcare professionals should be educated in palliative and end-of-life care.

The documents show general international agreement that care of the dying is a key part of acute stroke care, that stroke unit staff should be trained to recognise and meet palliative care needs and that patients and their families should be involved in decision-making. All agree that dying patients, including those with stroke, should have access to specialist palliative care services for management of complex symptoms or support with decision-making. In the UK, guidance states that dying stroke patients should be cared for in acute stroke units and have the opportunity for rapid discharge home (or to hospice or care

home) (Intercollegiate Stroke Working Party, 2012a) and that decisions should take account of prior directives or expressions of preferences.

In England, implementation of the recommendations has shown improvement over time. In 2010 over 10% (n=15) of English stroke units providing care beyond 72 hours did not admit patients dying from stroke (Intercollegiate Stroke Working Party, 2010). By 2012 the situation had improved (Intercollegiate Stroke Working Party, 2012b) and only four of the participating stroke units (n=205) still excluded patients on grounds of their requirement for end-of-life care.

In line with Scottish Government (2008) recommendations that end-of-life care pathways such as the LCP should be used in all care settings, NHS Quality Improvement Scotland and University of Glasgow (2010) recommended in a Best Practice Statement that end-of-life care pathways should be used to support care of patients dying after acute stroke.

By 2012, the LCP was used in 99% of English, Welsh and Northern Ireland stroke units (n=205) taking part in the Sentinel National Stroke Organisational Audit (Intercollegiate Stroke Working Party, 2012b). Scottish figures were not available as Scotland has a different audit system (Scottish Stroke Care Audit, 2015) that did not capture end-of-life data.

Importantly, the guidance documents (NHS Quality Improvement Scotland and University of Glasgow, 2010; Intercollegiate Stroke Working Party, 2012a; Holloway et al., 2014) did not specify how healthcare professionals working in stroke units might recognise end-of-life care needs or when to commence patients on end-of-life care pathways.

2.8.4 Advance directives and ‘living wills’

In addition to advance care planning when individuals become ill, it is possible for individuals while well to make legally binding statements refusing specific medical treatments or care in the future if they become incapacitated. These are known as advance decisions in England and Wales and advance directives in Scotland (General Medical Council, 2010) or are sometimes referred to as living wills (Degenholtz, Rhee and Arnold, 2004). Advance decisions are legally binding in England and Wales if they are found to be

valid and relevant to patient's current circumstances (NHS Choices, 2014) and advance directives are likely to be legally binding in Scotland (Macmillan Cancer Support, 2013).

Advance verbal statements of views regarding care preferences which are not legally binding should still be taken in to account by those deciding the care of incapacitated individuals (Department of Health, 2008; General Medical Council, 2010). The General Medical Council (2010) advised UK clinicians making care decisions, in the absence of a clear indication of an incapacitated patient's wishes, to seek information from the patient's family/carers. While advance directives or living wills did not emerge as key issues in this study, the role of families in informing end-of-life care decisions did. Relevant literature is discussed later in this review (2.10.2).

2.8.5 End-of-life care quality

The quality of end-of-life care in the UK has been scrutinised repeatedly over recent decades. In this section, the quality of care in the years leading up to this study is considered at some length. The section concludes with a brief consideration of more recent UK reports on care quality in order to outline the current context.

The LCP was developed with the intention of improving end-of-life care quality in acute hospitals (Ellershaw et al., 1997). Yet despite the LCP's rapid adoption in the UK (see 2.6) some deficiencies in UK end-of-life care quality were reported in the years following the LCP's publication. In a review of the care of older adults in 23 hospital organisations in England and Wales, the Healthcare Commission (2007) reported that the LCP was used in all organisations they inspected, but implementation was incomplete and hence provision of LCP-based care was patchy. Training on end-of-life care was available, but attendance was not mandatory and staff uptake was not universal. Additionally, a lack of private space i.e. side rooms for dying patients and their families was noted. Arrangements for end-of-life care were better developed in cancer settings than in non-cancer specialties. The report called for increased use of end-of-life care tools and for staff to be supported to improve end-of-life care.

The National Audit Office (2008) undertook an extensive review of end-of-life care in England. The investigation involved a literature review, economic modelling of national

(i.e. England) hospital statistics on care episodes, examining hospital records for 348 deaths in Sheffield, reviewing primary care organisations in three English local health authorities, focus groups and interviews with 12 terminally ill patients and with 16 carers, exploring their experiences of services. Surveys assessing end-of-life care provision and training were conducted with 141 primary care trusts (response rate 93%), 104 independent hospices (response rate 67%), 24 NHS hospices (response rate 60%), 134 care homes in England (response rate 9.5%), 901 doctors (response rate 79%) and 181 nurses. Unspecified numbers of stakeholders including Department of Health staff, voluntary sector and national charity representatives were also interviewed.

The National Audit Office (2008) reported that less than a third of doctors and one fifth of nurses received any pre-registration training in end-of-life care or communication and that education was therefore needed to enable staff to use care tools recommended by national policy. The National Audit Office (2008) also reported that nearly half of general nurses and two thirds of doctors were not trained to use the Liverpool Care Pathway, although the tool was recommended by the Department of Health (2008). The National Audit Office (2008) emphasised that while the LCP was anecdotally described by staff as beneficial for patient care, its direct benefit for patients was still to be demonstrated robustly. Despite the low response rate from the care homes survey, this was a comprehensive review of end-of-life care in England that indicated there was generally insufficient training in caring for and communicating with dying patients or in using the LCP.

Similarly Audit Scotland (2008) reviewed palliative care provision and costs i.e. including end-of-life care, in Scotland. All 14 Scottish NHS boards (i.e. regional health authorities) were surveyed as were 13 voluntary hospices and 2 children's hospices. Interviews were conducted with an unspecified number of NHS, hospice and primary care staff from five health board areas, representatives from Scottish Government, NHS Education for Scotland, the Care Commission, NHS Quality Improvement Scotland, the Scottish ambulance service and the Scottish Partnership for Palliative Care (a collaborative group of interested organisations). Surveys were also conducted with 85 district nurses (response rate 17%), 997 bereaved families and carers (response rate 19%), and focus groups held with 72 patients with a range of conditions.

The Audit Scotland (2008) findings indicated that palliative care quality varied across Scotland. Most end-of-life care was delivered by generalist staff. Cancer patients received 90% of national specialist palliative care provision despite cancer deaths representing less than 30% of all Scottish deaths. Patient and carers were most satisfied with hospice care and less satisfied with hospital and community-based care. Among carers, 25% reported that poor communication made the end of life more difficult. Five NHS boards used the LCP in all acute hospitals, two boards used it in all community hospitals and two boards used it in NHS hospices. The LCP was used in 12 voluntary sector hospices and by 25% of district nurses surveyed. Not all staff were adequately trained to provide palliative care. Therefore Audit Scotland (2008) recommended that the Scottish Government should promote LCP use in all care settings. The methods for the Audit Scotland (2008) review were less extensive than the National Audit Office (2008) and low response rates may have reduced the validity of the survey findings. Nevertheless the findings suggested that as in England, staff caring for dying patients required additional training, and that LCP 'roll-out' was ongoing.

The Healthcare Commission (2008) reviewed 7,500 complaints referred to them for independent review by NHS health organisations in England during 2006-2007. Fifty complaints (0.7%) primarily concerned palliative care. The Commission's investigators reported that patients and families did not receive enough information to be involved in making decisions about care. Investigators noted poor communication between professionals and between clinical areas. Often the transition from active treatment to end-of-life care was not clearly communicated and active treatment was continued unnecessarily. Patients generally lacked privacy or comfort, and their spiritual, cultural and psychological needs were poorly addressed. Referrals to specialist palliative care were made late or not at all. The Commission noted that the LCP had not been adopted in all the NHS organisations they investigated, and recommended that the pathway should be implemented, with relevant staff training.

In summary, when this study commenced, LCP use in English and Scottish NHS hospitals was increasing but not universal. The quality of end-of-life care was reported in some areas to be hampered by hospital infrastructure, staff training deficits and poor communication. End-of-life care was reported to be better organised in cancer care. Complaints about end-of-life care cited poor communication, inadequate physical care, inadequate spiritual or

psychological care, unnecessary treatment and lack of specialist palliative care involvement.

During this study, public concerns about end-of-life care quality triggered national debate in the UK, culminating in the Neuberger review (Neuberger et al., 2013), the withdrawal of the LCP and new recommendations to guide end-of-life care. This is discussed in section 2.15.

Yet problems with end-of-life care quality continue to be identified. The Parliamentary and Health Service Ombudsman (2015) reported twelve cases which they said were typical of complaints they received regularly about end-of-life care in NHS England. The frequency of complaints was not reported but according to the House of Commons Health Committee (2015), the Ombudsman received 220 complaints about end-of-life care from 2011-2014, 182 of which related to hospital settings. Recurrent issues included failure on the part of healthcare teams to recognise that patients were dying, inadequate symptom management, inadequate communication between healthcare professionals and patients and their families, poor out of hours service provision, insufficient care planning and delays with diagnoses and referrals. These issues are similar to the complaints reported previously by the Healthcare Commission (2008). While these findings suggest that the issues may be persistent problems in end-of-life care, it should be noted that they are typical of only a small percentage of care episodes.

Newer data from the period following this study appear more positive. The Royal College of Physicians (2016) reported findings from an organisational audit and casenote review (n=9,302) of deaths in 142 hospitals trusts in England. Data were collected July -Sept 2015 i.e. following withdrawal of the LCP in the UK. The Royal College of Physicians (2016) suggest that, despite concerns about reduced end-of-life care quality following withdrawal of the LCP, in comparison with their previous audits (see 2.5), end-of-life care has generally improved. For example imminent death was recognised in 83% (n=7,720) of cases and discussed with 79% (n=7,162) of relatives. Patients concerns were elicited in 84% (n=7,813) of cases and for 56% (n=5,209) of relatives. Individualised holistic care plans were documents in 66% (n=6,139) of casenotes. Training in end-of-life communication was provided for medical staff and nursing staff (registered and non-registered) by 62-71% of hospitals (n=88-100). Notwithstanding, areas for improvement

remain. For example seven-day face-to-face specialist palliative care service provision was provided by only 37% of hospitals (n=52).

On a larger scale, the Office for National Statistics (2016) reported generally positive findings from a survey of 21,320 bereaved relatives (response rate 43%) regarding the quality of end-of-life care received in NHS England by a deceased family member. More than three quarters of the sample (78%, n=11, 473) said that care was excellent or good, and reported that in the last two days of life their relative received oral or other fluids, or nutrition support (75%, n=9,837) while 81% (n=12,324) said their relative's pain was relieved. The majority (86%, n=15, 296) said they understood what they were told by healthcare professionals. Yet 16% (n=2,875) of respondents felt they didn't have enough time to ask questions and only around two thirds (69%, n=9,924) of respondents said that patients' emotional needs were addressed. Additionally, hospital care was rated as high quality less often (69%, n=6,382) than care in other settings such as care homes (82%, n=4,646) or hospices (79%, n=991). While these results appear generally encouraging, the findings suggest that improvements in end-of-life care are still required. Additionally the response rate, while reasonable was relatively low, and data for other parts of the UK are not available.

Overall, recent scrutiny of end-of-life care quality suggests that it is an enduring clinical issue requiring investigation and improvement. Therefore this study remains relevant.

2.8.6 Theoretical concepts in end-of-life care

In this section two theoretical concepts in modern end-of-life care are discussed. The concepts relate to awareness of dying and timing of dying. These concepts formed part of the study background, informed the study methods and were used in interpreting some of the findings. Their evolution and modern relevance is reviewed here.

In the 1960s Glaser and Strauss investigated end-of-life care in San Francisco hospitals. Several landmark publications emerged. Glaser and Strauss (1966) reported how clinicians disclosed diagnoses of dying to patients and families and in (1968b) described how clinicians handled uncertainties about the timing of dying. In further publications Glaser & Strauss (1968a) described their methods and later proposed an overarching social theory of

the societal role of hospitals in facilitating transitions from life to death (Glaser and Strauss, 1971). Findings from the first two publications, including their modern relevance, are considered here, while Glaser and Strauss's grounded theory method is discussed in Chapter Three (see 3.10.1).

In six Bay Area hospitals over a period of three years, Glaser and Strauss purposively selected specialties such as emergency, paediatric and oncology wards at each site in order to gather data on varied aspects of dying. At least four non-participant observers collected data through interviews, observing direct care or staff meetings and speaking with patients. Observations were varied by time of day and night and lasted from ten minutes to hours. Glaser and Strauss used an iterative process of data collection and analysis (see 3.10.1.1) and tested their developing theories in interviews with staff at ten European hospitals in Italy, Greece and Scotland. They also drew on data from their previous hospital studies in five South East Asian countries.

Glaser and Strauss (1966) reported patterns in the way that diagnoses of dying were shared with patients and their families and within the care team. They coined the term "awareness contexts" (p10) to define the extent to which patients and carers knew the diagnosis of impending death. These contexts were "closed awareness" (p29) where the clinicians knew but the patient didn't, "suspicion awareness" (p47) where clinicians knew and the patient only suspected, "mutual pretence" (p65) where all knew yet pretended not to, and "open awareness" (p77) where all parties knew and acknowledged the diagnosis of dying. Families could share patients' awareness of prognosis or could share awareness with clinicians while patients remained unaware.

Additionally, Glaser & Strauss (1968b) described temporal patterns, or trajectories, of dying, where death was the final event in a process of varying length. They suggested that dying trajectories have both duration and shape and described typical trajectories. These were:

- expected or unexpected quick deaths
- lingering deaths

- “suspended sentences” (p6) where patients could improve and survive albeit temporarily
- “entry/re-entry” (p6) where patients improved and relapsed over time, deteriorating slowly towards death.

Glaser & Strauss (1968b) reported a synergy between trajectories of dying and work arrangements in clinical areas. End-of-life care was organised according to the dying trajectory most commonly observed in each clinical specialty. Staff expected patients to die around the expected time and struggled to adjust their work pattern where the timing of dying was uncertain or atypical for the specialty. Nevertheless Glaser & Strauss (1968b) also identified strategies used by staff to handle prolonged trajectories. For example by “backstopping” (p202), nurses continued with routine tasks but checked on dying patients every few hours thereby maintaining a death watch while not disturbing their work order. Glaser & Strauss (1968b) suggested this approach helped staff to maintain the routine work flow of the ward. Not only were atypical trajectories difficult for staff to handle but lingering dying was also reported as distressing for nurses and doctors. In particular, an unexpected switch from a rapid death to a prolonged death was stressful for clinicians because it required emotional and practical disinvestment from one planned course of action and re-engagement with another.

Glaser and Strauss (1966, 1968b) did not report the precise number and range of clinical areas involved in their study, or the sample size and composition in the European interviews, or any data details from the previous Asian studies. Nevertheless other aspects of their reporting showed features subsequently suggested by Lincoln and Guba (1985) as enhancing the trustworthiness of a study (see Table 3-1). These included prolonged engagement in the field with persistent observation, the use of a varied sample, triangulation between data sources, which all enhanced credibility. Further the thick description of methods given in Glaser and Strauss (1968) enhanced the transferability of their findings and methods.

Evidence of temporal patterns in mortality in the acute phase of stroke is presented in 2.9.1. These patterns are consistent with the work of Glaser & Strauss (1968b), showing that while some patients die rapidly after stroke, others have a more lingering trajectory (Bamford et al., 1990).

Small & Gott (2012) investigated the modern relevance of Glaser and Strauss's work using a deductive secondary analysis of data from two nested qualitative studies (Gott et al., 2008; Small et al., 2009). The original semistructured interviews were undertaken with demographically varied samples of 40 patients with advanced heart failure (Gott et al., 2008) and 20 bereaved relatives (Small et al., 2009). Participants were identified purposively from a longitudinal multi-centre survey of palliative care requirements in 542 patients with heart failure and their relatives, recruited from 16 GP surgeries in four UK areas. In the original studies, verbatim transcripts were analysed inductively and emerging themes agreed by two coders, with exploration of divergent cases. In the secondary analysis, Small & Gott (2012) reported searching the aggregated thematic data for evidence of awareness contexts or dying trajectories but did not detail their analysis methods.

According to Small & Gott (2012), Glaser and Strauss's work was widely accepted internationally, influencing end-of-life care and social research methods at the time and subsequently. For example, Small & Gott (2012) describe a move towards openness in discussing terminal diagnoses and prognoses in health care over the intervening decades, attributing this at least in part to Glaser and Strauss.

From their secondary analysis Small & Gott (2012) reported awareness contexts in 21st century UK resembling those reported in the US by Glaser & Strauss (1966). Patients with advanced heart failure and their families were not told of their terminal prognosis or that the timing of their death was uncertain. However, as in Glaser & Strauss (1966), patients and families could pick up cues about prognosis from healthcare professional behaviours without explicitly being told. Hence Small & Gott (2012) concluded that awareness was either closed i.e. limited to the clinician or there was mutual pretence by all involved and that, like their predecessors, modern clinicians found it difficult to disclose poor prognoses. Clinicians cited the uncertainty of illness trajectories in heart failure as a reason to maintain closed awareness.

In Small & Gott's (2012) interpretation, this stance was more comfortable for clinicians than holding open discussions with patients and families about likely distressing outcomes. Yet Small & Gott (2012) also reported that some patients and families were content with closed awareness, not wishing details about likely outcomes. Small & Gott therefore

argued that open awareness should not necessarily be aspired to in every case. Although arguing that multi-morbidity and longer life expectancy have complicated dying trajectories in recent years and reduced the concept's relevance for clinicians who manage community-dwelling patients, Small & Gott (2012) identified links between awareness contexts and dying trajectories in patients with heart failure and concluded that Glaser & Strauss's work remained relevant.

Yet Small & Gott (2012) suggested that Glaser and Strauss did not sufficiently consider the relevance of social structures or the social resources of patients, families and health professionals in managing end-of-life care. The ability of individuals to exert influence on clinical decision-making is considered in more detail in 2.10.1. In particular, accepting the inevitability of trajectories was, Small & Gott (2012) argued, to ignore the ability of individuals to influence their situation.

Although Small & Gott (2012) provided no detail of their secondary analysis methods, markers of trustworthiness were reported for their original studies. The use of purposive varied samples from across the UK enhanced credibility and transferability, while the use of multiple coders strengthened dependability. Therefore the secondary analysis drew on trustworthy data although more information was needed to gauge the trustworthiness of the secondary analysis methods.

There is some evidence from Richards, Ingleton, Gardiner and Gott (2013) that not all patients or relatives wish to have open awareness about impending death. Richards et al. (2013) used recognised prognostic criteria to identify patients discharged from two hospitals in England who were likely to be in their last year of life. Semistructured interviews were then conducted with 15 patients and three of their relatives. Thematic analysis showed that while some patients and relatives sought all available information about their prognosis, others preferred not to know. Although the study did not reach data saturation, it had other markers of credibility e.g. the sample was varied by gender and diagnosis, data were coded independently and reviewed by third parties. Nevertheless in relation to the research questions for this study, participants were not in their final days or hours of life where communication and information needs may be different from the preceding months.

The research on awareness contexts and dying trajectories were relevant to this study because the LCP was intended to standardise end-of-life care planning and communication, both issues linked with temporal patterns of dying and disclosing prognoses.

2.8.7 Attitudes to death and dying

The findings of Small & Gott (2012) regarding clinicians' discomfort with discussing dying are consistent with other evidence that the UK public and doctors find conversations about dying to be difficult. In a UK online survey of 2000 members of the public and 1000 general practitioners, 63% (n=1287) of lay respondents reported discomfort in discussing death or dying with a friend or family member who was recently bereaved and one third of GPs (n=351) had never initiated a discussion about end-of-life wishes with a patient (ComRes, 2011). Further, the majority of lay respondents employed euphemisms to avoid the terms "death" or "dying" in conversations with a bereaved person. The most common euphemisms were: "passed away" (57%), "deceased" (23%) or "passed on" (18%) (p26). According to Smith & Kelly (2012) the use of euphemisms in discussing death and dying is a global phenomenon, with similar terms existing in many languages.

The use of euphemisms involving the LCP has been described in end-of-life care studies. In a phenomenological study with six ICU doctors and nurses in two hospitals in the UK Midlands, Walker and Read (2010) reported that in communications between healthcare professionals the LCP was used as a euphemism in reference to dying. The study was small and localised, and features commonly used to enhance credibility in phenomenological studies i.e. serial interviews and bracketing of the researcher perspective were not reported. In a qualitative study of LCP use for cancer patients in one English hospital, Freemantle and Seymour (2012) interviewed seven nurses and four doctors involved in the care of six patients who died. Nurses and doctors reported reluctance to initiate conversations with patients and families about dying and one nurse reported using the term 'on the LCP' as a euphemism for dying during discussions with families. Like Walker and Read (2010), the study was small and localised with limited transferability.

In summary, there is some evidence that the UK public and some healthcare professionals find conversations about dying to be uncomfortable. Further there is very limited evidence

that even where the LCP was used, discomfort could persist for healthcare professionals when discussing dying with patients and families.

2.8.8 Summary

In summary, despite improvements in stroke care there remains a substantial need for end-of-life care among patients admitted to acute stroke services. At the time this study began, the Scottish Government recommended using end-of-life care pathways such as the LCP for patients dying in all clinical areas. Despite efforts to improve end-of-life care, in the years before this study began several English and Scottish healthcare investigations reported deficiencies in clinical care, staff education, communication and infrastructure. There is some evidence that death and dying remain taboo conversation topics for some of the public and some health professionals. Landmark work from the 1960s identifying patterns in the management and disclosure of imminent death with patients and families is reported as having contemporary relevance.

Findings from the database searches are now considered in relation to the research questions for this study. First, literature on recognising dying is discussed and issues relating to stroke are considered in particular.

2.9 Recognising dying

Recognising dying has been described as a key clinical skill (Ellershaw and Ward, 2003). Eychmüller et al. (2013) argued that the concept of ‘diagnosing’ dying is rooted in a biomedical view. Such a view, they contend, fails to allow that dying is also a social phenomenon that includes the potentially relevant views of lay carers. For this reason, Domeisen Benedetti et al. (2013) use the term ‘recognising’ dying interchangeably with ‘diagnosing’ dying, to reflect the relevance of both clinical and lay views in identifying that patients are dying.

According to a discussion paper by Watts (2012), recognising that a patient is dying is a prerequisite to initiating end-of-life care pathways. Other prerequisites are multidisciplinary team agreement that the patient’s condition is irreversible and where possible, discussions with the patient and family. Watts (2012) searched three databases for

papers published since LCP inception i.e. 1997, to identify papers on decision-making leading to end-of-life care pathway use. Hand-searching and grey literature searches were also used. Inclusion/exclusion criteria and the number of search results were not reported.

Watts (2012) concluded that recognising dying is complex and that decision-making processes resulting in pathway use were under-researched. Watts (2012) identified that clinical inexperience, educational deficits and professional and organisational culture were all reported as contributing to the difficulties in recognising dying. Watts (2012) called for urgent investigation of decision-making related to end-of-life care pathway use in varied disease groups and clinical settings. Because of the limited number of databases searched and non-reporting of results it is possible that Watts (2012) omitted some relevant papers, yet subsequent studies are consistent with her findings.

In a systematic review of clinical indicators of dying in cancer patients, Eychmüller et al. (2013) found no evidence of clear indicators reliably associated with the dying phase, which they defined as the last seven days of life. Five databases were searched although these did not include Cochrane or Medline. Of 12 observational studies identified, ten focused on prognostic predictors and only three aimed to explore clinical indicators of imminent death. No sensitive and specific indicators of dying were identified. Although two studies agreed that fatigue, dyspnoea, pain and altered consciousness were common in the last days of life, Eychmüller et al. (2013) argued these terms were too vague to guide clinical practice. Eychmüller et al. (2013) suggested that more studies were required, although it is possible that had they searched more widely, other studies may have been identified. Arguing that recognising dying is not purely a medical event but is also a social or family event, Eychmüller et al. (2013) also recommended that the views of lay carers should be included in future investigations of the recognition of impending death.

Nevertheless two studies identified common observations used by healthcare professionals and by the public to recognise dying. First, a Delphi study involving 252 palliative health care professionals, volunteers and lay carers in seven European countries, Argentina and New Zealand identified seven key indicators used to recognise dying in cancer patients (Domeisen Benedetti et al., 2013). These were changes in breathing, particularly presence of rattle and changes in rhythm and pattern, general rapid clinical deterioration, irreversible decline in conscious or cognitive level, changes in skin colour, particularly peripheral shut-

down, inability to ingest fluids, restlessness and observers' intuition. Intuition was also reported as a key part of judging imminent dying.

In another study, changes in breathing patterns, and irreversible deteriorations in patients' muscle tone, conscious levels and vital signs were reported by Australian medical ward nurses (n=25) as signs of imminent death (Bloomer, Endacott, O'Connor and Cross, 2013). Both studies were well-conducted and because of their geographical spread are likely to be generalisable. Further, the views expressed by the palliative care specialists (Domeisen Benedetti et al., 2013) were similar to those of non-specialist nurses (Bloomer et al., 2013), strengthening the likelihood of transferability.

In summary, recognising dying is a precursor to providing end-of-life care. Yet there is little evidence that accurate diagnostic markers of dying exist, although clinical judgements used internationally to identify dying in practice have been described. The decision-making process culminating in a decision to use an end-of-life care pathway was under-researched. These findings underline the relevance of the research question on clinical decision-making which was investigated in this study. The particular case of stroke care is now considered.

2.9.1 Prognostication after stroke

There is evidence that 30-day mortality post-stroke is related to the type of stroke involved. For example, the Oxfordshire Community Stroke Project (OCSP) was a landmark population-based study conducted to describe the natural history of stroke (Bamford et al., 1988) and from which several key papers emerged. The OCSP studied a prospective cohort (n=675) of all incident cases of first-ever stroke over four years in 50 GP practices in one UK region with an approximate population of 105,000. Patients were identified via hospitals and GPs and followed up for morbidity assessments by research nurses at one, six, 12 months and then annually for five years. Mortality follow up continued indefinitely via an NHS registry. Bamford et al. (1990b) reported that the 30-day case fatality rate was significantly higher for patients with primary intracerebral haemorrhage than for ischaemic stroke (RR 4.1; 95% CI 3.4-4.9).

Further, Bamford et al. (1990b) reported that in the 30 days following acute stroke, deaths from primary intracerebral haemorrhage were more likely within the first 72 hours and in association with neurological causes, while deaths from ischaemic stroke were more likely to occur after the first week and were often associated with the complications of immobility such as pneumonia or pulmonary embolism. Additionally, Bamford et al. (1991) described clinically distinct subtypes of ischaemic stroke relative to the circulatory territory of infarct, where mortality varied between subtypes. Case fatality at 30-days, six months and one year was higher in patients with total anterior circulation infarct (TACI). Table 2-2 shows the variations in 30-day case fatality rates among the stroke subtypes identified in the OCSF.

Table 2-2 Variations in 30 day case fatality rates among stroke clinical subtypes. Adapted from Bamford et al., (1990b, 1991)

Stroke type	Number of subjects	30 day case fatality rate n (CFR%)
<i>Ischaemic stroke</i> (all subtypes)	543	56 (10.3%)
Lacunar infarct	137	3 (2.2%)
Total anterior circulatory infarct	92	36 (39.1%)
Partial anterior circulatory infarct	185	8 (4.3%)
Posterior circulatory infarct	129	9 (7.0%)
<i>Haemorrhagic stroke</i>		
Primary intracerebral haemorrhage	66	34 (51.5%)

The internal and external validity of the OCSF study were enhanced by its exhaustive efforts to identify and follow up all cases, thereby ensuring a comprehensive and generalisable sample. Subsequent studies have replicated the findings of increased 30-day mortality for patients with cerebral haemorrhage and with TACI.

For example Hankey et al., (2000) studied five-year mortality in a cohort of 362 patients in Perth, Australia with first ever stroke, and reported that primary intracerebral haemorrhage was associated with higher 30-day mortality than ischaemic stroke. Further, Saposnik et al. (2008) studied a consecutive cohort of patients with ischaemic stroke admitted to Canadian stroke centres over a 20 month period. Thirty day mortality was predicted by stroke severity, subsequent neurological deterioration in hospital, not receiving thrombolysis and not being assessed by a stroke team. Age, comorbidity as measured by the Charlson Co-morbidity Index and in-hospital pneumonia were also

associated with 30-day mortality. Additionally in an Israeli national cohort of 1,079 first-ever ischaemic stroke patients, Koton, Tanne, Green and Bornstein (2010) reported that higher 30-mortality was significantly associated with TACI (HR 4.9, 95% CI 1.6-15.2). Stroke severity measured by National Institutes of Health Stroke Scale (NIHSS), decreased conscious levels, increasing age, temperature and glucose level on admission also significantly predicted 30-day and three year mortality.

Attempts have been made to condense mortality predictors into working clinical models for prognostication. Counsell, Dennis, McDowall and Warlow (2002) tested three predictive models for 30-day survival and survival at six months without disability, using logistic regression with combinations of variables shown in earlier studies to be significantly associated with survival. Investigators blinded to outcomes used data from 530 patients in the OCSP study to establish independent predictors of outcome, combined in three models. The models were validated by comparing against data from three other prospective stroke cohorts in Italy, Australia and Edinburgh. A model using six readily available clinical variables (age, independence in activities of daily living pre-stroke, living alone, verbal score on Glasgow Coma Scale, arm power, ability to walk) performed similarly to more complicated models (Area Under Curve 0.84-0.88). Nevertheless, the Six Simple Variables (SSV) model did not perfectly predict outcome and was not shown to be better than physicians' judgement. In a later study to validate the SSV model in a cohort of 537 patients in Scotland assessed within six hours of ischaemic stroke onset, Lewis, Sandercock and Dennis (2008) reported an area under the ROC curve of 0.73 for 30-day survival and accordingly cautioned that although the model was useful for stratification in clinical studies, it is not precise enough for decision-making in individual cases.

In a brief literature review incorporating one case study of a patient with stroke, Pullicino (2012) criticised the lack of evidence-based prognostic indicators guiding LCP use. He argued that the LCP was therefore used for patients based only on the subjective predictions of clinicians and hence that using the LCP was likely to invoke self-fulfilling prophecies resulting in excess patient deaths. In a US clinical guideline on end-of-life care in acute stroke, Holloway et al. (2014) similarly suggested that stroke clinicians' cognitive biases may lead to overly pessimistic prognostication and decision-making in acute stroke. According to Holloway et al. (2014), such prognostic biases may be operationalised in early DNR orders and a tendency to withdraw treatment. Holloway et al. (2014) therefore

recommended that validated prognostic models are used to inform clinical thinking regarding likely outcomes, but cautioned that such models have not been tested in end-of-life stroke care and should not be used as a basis for treatment decisions.

In summary, predictors of mortality and temporal patterns of mortality in the acute phase of stroke have been identified. Prognostic models are accurate enough to use in clinical research and may inform clinical decision-making for individual patients but are not substitutes for physicians' judgement. Therefore this study sought evidence of any prognostic factors considered by clinicians in end-of-life decision-making, specifically decisions to use an end-of-life care pathway, by investigating prognostic variables associated with decisions to use the LCP.

2.9.2 Recognising dying in acute stroke care

Recognising dying has been acknowledged as a challenge in acute stroke care. For example Haig (2009) criticised the LCP criteria for recognising dying (see 2.4) i.e. patients being bedbound, semi-comatose, only able to take sips of fluid and unable to swallow tablets. Haig (2009) argued that these apparent indicators of imminent death are also similar to the clinical features of stroke from which patients might recover. Several studies indicate that some UK stroke unit staff struggle with recognising dying, including units where the LCP was being used, and these are now discussed.

Groves, Hough and Jack (2011) suggested that difficulties in recognising dying may limit the use of end-of-life care pathways. From semistructured interviews with nurses (n=7) and doctors (n=9) working in non-cancer settings within one UK district general hospital, Groves, Hough and Jack (2011) identified that difficulties in recognising dying were barriers to using an end-of-life care pathway and that training in using care pathways varied widely. Further evaluation of Groves Hough & Jack (2011) was not possible because only a conference abstract was available.

In three hospital sites in the north of England, Burton and Payne (2012) conducted group interviews with 29 stroke clinicians including doctors, nurses and allied health professionals, investigating palliative care in acute stroke services. Participants said they struggled with judging if stroke patients were dying because the possibility of recovery had

to be considered. Consequently decisions were often delayed and end-of-life care was frequently initiated late. Although Burton and Payne (2012) sampled from a range of hospital sites, increasing the transferability of their findings to other stroke services, further details of the settings were not provided. For example, details about participants were not reported beyond identifying numbers from various disciplines. Therefore it is unclear how often the participants provided end-of-life care or how much previous training and experience they had in caring for dying patients. Data saturation was not reported. Additionally, Burton and Payne (2012) did not report what parameters clinicians used to make judgements about dying or if an end-of-life care pathway was used in the stroke units studied.

Gardiner, Harrison, Ryan and Jones (2013) identified that stroke unit staff encountered difficulties in making transitions from active treatment to end-of-life care. As part of a wider study of care quality, Gardiner et al. (2013) conducted focus groups and interviews with 66 stroke healthcare professionals including doctors, nurses and therapists across nine hyperacute, acute and rehabilitation stroke units in the north of England. Snowball sampling was used to recruit participants within purposely selected disciplines, multiple coders contributed to the thematic analysis and data saturation was reported. In Gardiner et al. (2013) the LCP was used by participating stroke units, but some respondents reported similar difficulties as the participants in Burton and Payne (2012). Recognising dying and judging the right time to initiate LCP use was problematic. The fact that the LCP was available did not apparently help staff identify when to use it.

Yet although Gardiner et al. (2013) used a large, varied sample and reported data saturation thereby enhancing credibility, some risk of bias remains. For example, the use of snowball sampling may have produced a sample with particular views on end-of-life care, and as with Burton and Payne (2012), participants' training and experience in providing end-of-life care was not reported. Hence it is unclear to what extent difficulties in recognising dying following acute stroke related to inexperience or to the clinical characteristics of stroke.

In summary, recognising dying after acute stroke was reported to be clinically challenging at times. The studies by Groves, Hough and Jack (2011), Burton and Payne (2012) and Gardiner et al. (2013) did not report parameters used by stroke unit staff to identify when

patients were dying, or explore the strategies used by staff to address the challenges of recognising dying. Therefore this study addressed the evidence gap by exploring how healthcare professionals recognised when stroke patients were dying, and by investigating clinical decisions to use the LCP.

2.9.3 Timing and the recognition of dying

Some studies suggest that in acute hospitals impending death is often recognised relatively shortly before death occurs, although authors argue that late recognition does not preclude the provision of end-of-life care.

For example, Twomey, McDowell and Corcoran (2007) conducted a retrospective casenote audit of deaths in one month (n=25) prior to LCP introduction in a UK Medicine for the Elderly unit. Six (24%) of the patients had a primary diagnosis of stroke. The audit showed that diagnoses of dying were made 24-48 hours before death for 48% of patients (n=12) and less than 24 hours before death for five (20%). Two patients (8%) had sudden deaths. Symptoms such as dyspnoea, pain and agitation were documented for up to 13 (53%) patients, of whom nine (69%) were prescribed treatments for symptom relief. Nevertheless Twomey, McDowell and Corcoran (2007) concluded that in their sample dying was often recognised in time to institute some form of end-of-life care but argued that improvements could be made. Nevertheless, the sample was small and hence generalisability was limited.

In another study, Gibbins et al. (2009) reviewed casenotes for 100 deaths in a UK acute hospital trust during a three-month period, prior to implementation of an end-of-life care pathway in the organisation. From a total of 453 deaths, casenotes were randomly selected for screening (n=154) until 100 were identified where the researchers judged death was possible to anticipate i.e. sudden deaths were excluded. The casenotes were screened by two senior clinicians to evaluate whether death could have been anticipated four hours or more ahead of the actual death. The clinicians used their own judgement and the LCP criteria for recognising dying (bed bound, unable to swallow, semi-comatose – see 2.4). An independent palliative care consultant reviewed 25% of the reviewers' evaluations. The sample included 15 patients with a primary diagnosis of stroke. The time lapse from anticipation of dying to the death itself varied from four hours to 16.5 days. Recognition of

dying occurred less than 12 hours before death for 32% of patients and within 24 hours before death for 49%.

The findings appear consistent with those of Twomey, McDowell and Corcoran (2007), because Gibbins et al. (2009) concluded that while clinicians were able to recognise dying in time to provide some aspects of end-of-life care, recognition occurred close to death for large numbers of patients. Gibbins et al. (2009) used expert opinion for data evaluation and was therefore open to subjective bias, although this was mitigated by the peer review. Nevertheless their evaluation may have been weakened further by including the LCP criteria for recognising dying. These criteria were criticised by Haig (2009) as contradictory in relation to acute stroke (see 2.9.2). Therefore Gibbins et al. (2009) possibly over-estimated clinical opportunities to recognise dying, particularly in stroke patients. Further, Gibbins et al. (2009) did not report strategies used by clinicians to make the diagnosis of dying.

Gott, Ingleton, Bennett and Gardiner (2011) used focus groups with 58 primary care and hospital healthcare professionals in two English cities to explore how clinicians recognised patients' palliative care needs. The study's main focus was the recognition of palliative care needs in the year before death but some data emerged relating to end-of-life care in the last days of life. Participants reported difficulties in gauging the reversibility of patients' clinical deterioration, with the result that imminent death was often recognised late in hospital, particularly for patients with a non-cancer diagnosis. The late recognition of dying made it difficult to meet patients' care preferences e.g. discharge for end-of-life care at home. Hierarchical structures inhibited junior staff from communicating their assessments of patients' needs to colleagues. The study had several markers of trustworthiness. A large and demographically varied sample was used, data were coded independently with review and agreement of themes and theoretical saturation was reported. However, Gott et al. (2011) did not report if an end-of-life care pathway was used in the study sites and it is not clear if any participants worked in acute stroke units.

Adams et al. (2013) retrospectively audited 50 of the 53 deaths occurring in a UK stroke unit over a nine month period, where the LCP was used to support care in 39 (78%) cases. The mean time lapse from admission to LCP commencement was 17 days. Although 16 patients (41%) died within 24 hours of LCP commencement, the mean LCP duration was

5.3 days (range 0-17 days). Hence for at least some of these stroke patients, dying was recognised in time to make key decisions. The audit was reported in a conference poster abstract, precluding further review. Additionally, Adams et al. (2013) did not report figures for stroke patients who died without the support of the LCP.

Although the studies by Twomey, McDowell and Corcoran (2007) and Gibbins et al. (2009) were carried out in acute units where an end-of-life care pathway was not used, their findings were similar to Adams et al. (2013) where the LCP was in place i.e. all three studies identified that while up to nearly half of patients died in under 24 hours, others survived longer and some for more than a week. Therefore the three studies suggest that even though dying is recognised relatively close to death there is often still sufficient time provide some aspects of end-of-life care. Although these studies included stroke patients, the methods used by healthcare professionals to recognise dying are unclear. Further, although Adams et al. (2013) reported findings from a stroke unit, recognising dying in stroke patients who died without the support of the LCP is not reported.

2.9.4 Recognising dying – summary

In summary, recognising dying is a precursor to using an end-of-life care pathway, yet recognising dying is reported to be particularly difficult in stroke care. Nevertheless, although reliable indicators of impending death are poorly described, common strategies used by palliative care clinicians and acute hospital nurses to recognise dying are reported. Yet such strategies are not reported in stroke care. Further, impending death is often recognised late in acute hospitals, limiting the time available for end-of-life care. This study investigated clinical indicators recorded and reported by healthcare professionals in recognising when patients were dying after stroke. Therefore the casenote study included patients dying with or without LCP-based care in order to explore any differences in indicators between groups.

Prior to this study little was reported about how healthcare professionals recognised dying in stroke patients and therefore resultant decision-making in using end-of-life care pathways after stroke was poorly understood. Literature relating to decision-making is now

reviewed, with a particular focus on stroke care and the decision to use an end-of-life care pathway. The role of patients and families is evaluated and the dearth of literature on decisions to use end-of-life care pathways is identified.

2.10 Decision-making

2.10.1 Shared decision-making

UK guidance states that patients with capacity should decide their own end-of-life care in consultation with the clinicians caring for them (General Medical Council, 2010). Such shared decision-making has been defined as involving at least two parties i.e. clinician and patient, exchanging information in order to reach agreement on a treatment plan (Charles, Gafni and Whelan, 1997). According to Bélanger, Rodríguez and Groleau (2011), in the Western world over recent decades, medical decision-making has moved from paternalism to a shared model.

However, there is some evidence from a general practice context unrelated to end-of-life care that responsibilities in shared decision-making can be misperceived. Edwards & Elwyn (2006) reviewed audio recordings of 61 consultations between patients and eight UK GPs trained in shared decision-making. The recordings were assessed for evidence of shared decision-making by two researchers who used a validated scoring tool. Semi-structured telephone interviews were conducted 3-28 days after consultation with a purposive sample of 17 of the patients. The sample had varied demographics and health conditions and represented each doctor once at minimum. The interviews explored decisions made during the consultation, identified the decision-maker and covered patient satisfaction with decision-making and outcome.

All 17 consultations scored highly for patient involvement in decision-making, yet around half of interviewees stated that they alone had made the intra-consultation decision, and the other half reported that decision-making was shared. Nevertheless most participants were satisfied with the process of information sharing that preceded the decision. The few who were dissatisfied with their consultations tended to prefer a paternalistic model and wished the GP had decided care for them. Edwards & Elwyn (2006) suggested that patients may describe responsibility for making a decision in a way which does not align with

theoretical models, and recommended that clinicians check patients' preferences for decision-making before and during consultations.

Edwards & Elwyn's study was small yet some aspects enhance its trustworthiness. The sample was purposively chosen to include all participating GPs and a varied sample of patients, enhancing credibility. Further, data from multiple sources were compared and contrasted. On the other hand, the time lapse between consultations and interviews may have introduced recall bias and data collected immediately post-consultation might have been more trustworthy.

Gafni and Charles (2009) made a suggestion consistent with Edwards & Elwyn's (2006) findings i.e. that patients and physicians can choose whether paternalism or shared decision-making is preferable in particular clinical situations. Gafni and Charles (2009) described decision-making using the concept of agency, suggesting that physicians were traditionally seen as proxy agents for patients. According to Hewson (2010), in social theory the term 'agency' refers to the ability of individuals to exercise freewill and influence events in the world around them i.e. being active in a social situation rather than passive, being a subject rather than an object, being an actor rather than being acted upon. Agency may be exercised individually, collectively or by proxy and agents have varying degrees of power, depending on their abilities and resources. Further, agency may be constrained by the social structures in which individuals operate.

In summary, UK and Scottish guidance directs that where possible patients should be involved in deciding their end-of-life care. Yet there is some evidence of subjective perceptions of responsibilities regarding shared decision-making in general practice, with some dissatisfaction where preferences for decision-making styles were unmet. It has been suggested that doctors may act as powerful agents for patients, although a social definition of agency allows for individuals as well as their proxies to exercise influence. Shared decision-making in end-of-life care, including the role of family proxies and their power are now discussed.

2.10.2 Family involvement in end-of-life decision-making

Where patients lack capacity, clinicians should seek information about the patient's preferences from their families or relevant others (General Medical Council, 2010). UK guidance also states that unless legally appointed to represent the patient, relatives have an advisory role in decision-making, not an executive one, and clinicians should make this clear. Notwithstanding, the guidance also states that with regard to clinically assisted nutrition and hydration in incapacitated patients expected to die within hours or days and where risk and benefit are balanced, family certainty about the patient's wishes should be a deciding factor (General Medical Council, 2010). While patients whose care was explored in this study had not made advance directives or living wills (see 2.8.4) many were affected by incapacity. Consequently the role of their families in informing end-of-life care decisions was an important feature in care and relevant literature is now explored.

There is some evidence that relatives experience discomfort when acting as proxies for incapacitated relatives. In a qualitative study, Dreyer, Førde and Nortvedt (2009) interviewed 15 relatives of 20 incapacitated decedents in a varied sample of ten Norwegian nursing homes between two and 12 months post-bereavement. Six of the decedents were admitted to hospital with suspected strokes at the end of their lives. Their place of death was not reported. Two researchers undertook thematic content analysis and data saturation was reported, enhancing study credibility. Relatives who had discussed treatments with clinicians reported feeling responsible for decisions made and worried that they had misrepresented the patient's wishes or that they put their own views ahead of the patient's. Conversations with clinicians had centred on medical treatment, nutrition and hydration with no discussion of the relatives' role in making decisions.

Evidence also emerged from a related study that relatives' views strongly influence end-of-life decision-making for incapacitated patients. Dreyer, Førde and Nortvedt (2010) reported findings from interviews with nine doctors and 10 nurses from the same nursing homes as the 2009 study. Interviews explored decision-making in respect of treatment limitations at the end of life, using the same analytical methods as the previous study and similarly reporting data saturation. Clinicians reported they sometimes overrode their own judgement because of pressure from relatives, giving futile life-prolonging interventions to dying patients, or hospitalising dying patients unnecessarily.

Dreyer, Førde and Nortvedt reported Norwegian legal frameworks and guidance on end-of-life decision-making for incapacitated patients resembling those in the UK. Their studies were credible and included stroke patients. Nevertheless, given the varied time-lapses between bereavement and interviews, Dreyer, Førde and Nortvedt's (2009) interview data may have been subject to recall bias. Further, Dreyer, Førde and Nortvedt did not report if an end-of-life care pathway was used in their study sites, the studies did not include acute hospitals and as they were conducted in one country their studies have limited transferability.

Clinicians have reported increased confidence in handling discussions with families after LCP introduction. Di Leo et al. (2011) conducted focus groups with five doctors and eight nurses in a 72-bedded Italian medical ward, with two groups (n=13) held before and two groups (n=11) held two months after LCP introduction to the ward. Focus group discussions explored common problems in providing end-of-life care in the clinical area, expectations of the LCP and the degree to which those were met. Thematic analysis was conducted independently by two researchers and agreed by a third researcher. In the focus groups prior to LCP introduction, healthcare professionals described difficulties in communicating with relatives. Nurses reported that families meddled with decision-making such as the decision to begin morphine administration. All healthcare professionals said they felt pressured by relatives in various aspects of care and communication. Although in the focus groups after LCP implementation healthcare professionals reported greater confidence in communicating with relatives, the effect on family influences on decision-making was not reported. Yet the study had limitations. Although Di Leo et al. (2011) reported independent scrutiny of coding and analysis which enhanced their study's trustworthiness (see 3.11.2), nevertheless the sample size was relatively small and data saturation was not reported. Further, the study was conducted in one site only, limiting its transferability. Therefore, an evidence gap remained regarding family involvement in end-of-life decision-making in clinical areas where the LCP was used.

It has been reported that relatives acting as proxies in end-of-life decisions experience enduring discomfort about their role. In a systematic review of 40 studies, Wendler and Rid (2011) examined the effects on proxies of deciding end-of-life treatments. Twenty five papers reported data collected within a year of the decision-making event. Although reported decision-making appeared to be shared and most studies found participants were

satisfied with the process, around 30% experienced residual discomfort about their responsibilities and questioned whether they had made the right decisions, reporting high mental and emotional stress levels. However, almost half the studies had low or unreported response rates, most were from the US and none from the UK. In relation to this study it is unclear if any of the reported decisions related to end-of-life care pathway use. Nevertheless the findings are consistent with those of Dreyer, Førde and Nortvedt (2009), indicating that some relatives experience discomfort about their decisional responsibilities for some time after bereavement.

Evidence regarding family involvement in LCP-related end-of-life decision-making in the UK is limited. English audit data showed that where the LCP was used, staff communicated with relatives about the plan to use the LCP in a median of 71% of cases (IQR 65-80%) in the 121 participating hospitals (Marie Curie Palliative Care Institute Liverpool and Royal College of Physicians, 2011). The extent to which relatives were involved in deciding to use the LCP was not reported.

In summary, UK guidance directs that for incapacitated dying patients, family views of patients' wishes should be considered in deciding care. There is some evidence that relatives experience enduring discomfort about their perceived responsibility for decisions and that family views may strongly influence care decisions. This evidence arose from small European qualitative studies and one US systematic review. UK figures suggest that families were informed of the decision to use the LCP for their relative, but their role in deciding to use end-of-life care pathways was not reported. Although some studies included stroke patients they did not primarily investigate stroke care. The particular case of stroke care is now considered.

2.10.3 Families and end-of-life decision-making in stroke care

Rogers and Addington-Hall (2005) reported a qualitative study in one UK acute stroke unit in an urban teaching hospital. No end-of-life care pathway was used in the unit. Direct observation and interviews with staff and relatives were used to investigate prospectively the care of 22 incapacitated stroke patients identified by healthcare professionals as imminently dying. Data were collected 8am-2pm per weekday over a six month period.

Analytical methods were not reported beyond the use of constant comparison of data. Findings from observations and staff interviews, but not relatives' interviews, were reported.

Rogers and Addington-Hall (2005) reported that 20 of the 22 patients died. Uncoordinated communication between medical teams resulted in inappropriate tests and treatment being administered to dying patients. Thirteen deaths occurred within the first five days and seven occurred more than five days following admission. Clinical decision-making was reported as more difficult for the patients who survived beyond five days. Decisions about artificial feeding were particularly difficult, with families less willing than nurses and doctors for active treatment such as artificial feeding. Nurses were sceptical about seeking family views on feeding, believing the decision belonged to doctors. Artificial feeding and other active treatments were sometimes given to prevent families feeling responsible for decisions to withhold the treatments, rather than because the treatments were in the patient's best interests.

Although Rogers and Addington-Hall (2005) reported prolonged engagement in data collection, overnight and weekend decision-making was omitted. Further, data analysis was not clearly described and findings from interviews with relatives were not reported. Hence the study offers limited understanding of family experiences of decision-making.

One Canadian study indicated that feeding and hydration decisions in end-of-life stroke care could raise dispute. Blacquiere, Gubitz, Dupere, McLeod, & Phillips (2009) conducted a retrospective records review (n=104) of deaths in one Canadian stroke unit over a two year period. One hundred and four interactions were documented between staff and families, of which 46 (44.2%) concerned feeding and hydration issues. Of those, 21 (45.6%) interactions involved conflict. However, the nature of the conflicts was not specified i.e. whether families or staff wished treatment to be withheld, continued or withdrawn. The authors did not report if an end-of-life care pathway was used in the stroke unit.

Young, Rogers and Dent (2009) used a validated postal questionnaire (Views of Informal Carers Evaluation of Services - VOICES) to investigate predictors of satisfaction with end-of-life stroke care. A random sample of 183 friends or relatives (response rate 37%) registering stroke deaths in central London during 2003 were surveyed and the subset

relating to hospital deaths (n=165) was analysed. More than half the participants (n=104, 56.8%) reported care as excellent or good overall. Further, Young, Rogers and Dent (2009) dichotomised responses into 'excellent care' (n=49, 29.7%) or 'not excellent' i.e. good, fair or poor (n=98, 59.4%). Logistic regression showed that proxies who reported being involved in care decisions as much as they wanted were significantly more likely to rate care quality as 'excellent' (OR 3.96, 95% CI 1.48 - 10.59). Nonetheless, the survey's low response rate suggests that broader opinion and experience may not have been represented. Additionally the retrospective design and dependence on death certificates may have limited accurate case identification. Young, Rogers and Dent (2009) did not report if an end-of-life care pathway was used in the cases reported by participants.

Payne, Burton, Addington-Hall and Jones (2010) used semistructured interviews to explore the end-of-life care preferences of 28 patients and relatives (n=25) recruited purposively from a larger prospective cohort of consecutive stroke admissions (n=191) to two hospitals in northeast England. Data were analysed thematically. Multiple coders and member checking were used to enhance credibility, although data saturation was not reported. Uncertainty of prognosis was said to hamper decision-making and some relatives felt frustrated that staff could not predict likely outcome. Relatives of patients who were dying reported limited opportunities for involvement in clinical decision-making, with resuscitation being the decision with which they were most commonly involved. The study was small and although it involved two hospitals was conducted in one geographical area, thereby limiting transferability. It was not reported if an end-of-life care pathway was used in the stroke units studied.

In the Netherlands, de Boer et al. (2015) interviewed a purposive sample of 15 relatives who had participated in decision-making for family members admitted to four acute hospitals and one nursing home with severe stroke. It was not reported if an end-of-life care pathway was used in the units studied. Ten of the index patients died in the acute phase of their stroke. Interviews were conducted at two to six months after the care episode and explored relatives' roles in decision-making, including role perception and information exchange. Qualitative thematic analysis and peer review of coding were used, and data saturation was reported, enhancing study credibility. De Boer et al. (2015) reported that relatives experienced stress because the speed of stroke onset did not allow them sufficient time to think decisions through. Consequently relatives reported they had to adapt later to

the emotional impact of their involvement. Some relatives reported being asked by doctors to make treatment decisions and struggled with an associated sense of unwanted responsibility. Others were reluctant to express their opinions relating to treatment, preferring doctors to make decisions unilaterally.

De Boer et al. (2015) was a small qualitative study conducted in one country and although demonstrating aspects of rigour was nonetheless limited in its transferability. Yet the findings are consistent with Edwards & Elwyn's (2006) UK study of shared decision-making in general practice, because some participants in each study preferred paternalistic approaches to decision-making. The findings are also consistent with those of Dreyer, Førde and Nortvedt (2009) in a mixed stroke/non-stroke population where enduring discomfort from perceived decisional responsibility was reported.

In summary, no papers explored the decision to use an end-of-life care pathway in stroke care. Clinical decision-making in stroke was more challenging where dying trajectories were prolonged. Feeding and hydration decisions were particularly difficult and could engender dispute between families and healthcare professionals. One study reported limited opportunities for families to contribute to decisions other than those related to cardiopulmonary resuscitation. Relatives of dying stroke patients reported enduring discomfort from perceived responsibility for decisions and unmet preferences for decision-making style. Satisfaction with involvement in decision-making was a predictor of overall satisfaction with care quality.

2.10.4 The role of healthcare professionals in deciding end-of-life care

Two New Zealand studies (Thurston and Waterworth, 2012; Clark, Sheward, Marshall and Allan, 2012) and one UK study (Freemantle and Seymour, 2012) conducted in clinical areas where the LCP was used reported that experienced nurses led the recognition of dying, which prompted end-of-life decision-making. Methods and findings of each study are reported first and then aspects of rigour across the three studies are reviewed.

Thurston & Waterworth (2012) conducted focus groups and semi-structured interviews with 10 registered nurses and five senior nurse managers working in medical and surgical areas in one New Zealand hospital where the LCP was used. Thematic analysis was used,

with independent review of coding and member checking of transcripts to enhance credibility. Nurses reported that since LCP introduction they felt more confident in telling doctors when they thought patients were dying and in broaching the topic of dying with families, although some doctors occasionally opposed LCP use.

Similarly, in two acute wards in one New Zealand hospital where the LCP was used Clark, Sheward, Marshall and Allan (2012) surveyed 41 (response rate 18%) registered nurses, doctors, social workers and allied health professionals. Focus groups (18 participants) were also conducted with doctors, nurses and allied health professionals. Thematic content analysis was used for qualitative data and resultant themes reviewed by the research team. Survey respondents believed using the LCP improved their ability to recognise dying. In focus groups, doctors reported that using the LCP empowered nurses to alert colleagues when patients were dying, thereby activating end-of-life decision-making. Nonetheless nurses reported that some doctors avoided using the LCP with its explicit recognition and discussion of dying, preferring to use euphemisms like “for comfort care” (Clark et al., 2012;p472). This precluded clear decision making and management of the dying phase. Clark et al. (2012) concluded that further studies were required to investigate the recognition of dying and subsequent changes to the direction of care.

In the UK, Freemantle & Seymour (2012) explored decisions to use the LCP for patients in three oncology wards in one English hospital. Semistructured interviews were conducted with seven nurses and four junior doctors caring for six decedents. Narrative and thematic analysis were applied, although other details of analytic rigour were not reported. Participants reported that senior doctors had limited time to observe patients. Therefore the views of others in the team, usually experienced nurses, were needed to recognise that patients were dying and initiate decisions regarding LCP use. Some senior doctors were reported to avoid making end-of-life decisions but as senior doctors were not sampled, their views could not be reported. Freemantle and Seymour (2012) concluded that further studies were required to investigate LCP use at weekends and out-of-hours.

Collectively the studies suggested that nurses were often first to recognise dying and suggest LCP use. Using the LCP was reported to increase nurses’ confidence in their ability to recognise and communicate to colleagues that patients were dying. Yet conflict could arise within teams, with doctors sometimes avoiding or opposing decisions to use the

LCP. In summary there was limited qualitative evidence that decisions to use the LCP were not the sole domain of doctors but required input from the wider team, particularly nurses.

The three studies possessed limited indicators of rigour. All had limited transferability as they used small samples from single study locations. Although two studies (Thurston and Waterworth, 2012; Clark et al., 2012) used second checkers for coding, none reported data saturation, limiting their credibility. The response rate to Clark et al.'s (2012) survey was low, limiting its internal validity. Although these studies investigated end-of-life decision-making relevant to the LCP they had methodological limitations and did not address stroke care, an area reported to be particularly challenging (see 2.9.2). Nevertheless the consistency of findings across the international locations may strengthen their transferability.

A casenote audit (n=50) of LCP use in a UK stroke unit (Adams et al., 2013) indicated that 80% of decisions to use the LCP were made by stroke consultants, with the rest being made by other consultants or middle grade doctors. However, this was published as a conference abstract hence further scrutiny is not possible. The abstract did not report contributions from the wider multidisciplinary team prior to the senior doctor signing the LCP form. The role of stroke team members in recognising dying and resultant decision-making was therefore undescribed prior to this study.

2.10.5 Decision-making - summary

End-of-life decision-making should, like other healthcare decisions, be shared between patients and their healthcare professionals. Where patients lack capacity, family views should be considered by healthcare professionals making decisions. In studies of general medical, cancer and stroke care, families have reported discomfort with the role of proxy informant and some healthcare professionals have reported departing from normative practice to accommodate strong family opinions about end-of-life care. Family roles in deciding end-of-life care pathway use have not been reported in general settings or in acute stroke care. There was some qualitative evidence that decisions to use the LCP were often triggered by nurses and subsequently involved the wider multi-disciplinary team but family involvement was not investigated.

Therefore to investigate the clinical decision-making involved in placing patients on an end-of-life care pathway, this study explored the role of both families and the multidisciplinary team in deciding to use an end-of-life care pathway for patients dying after acute stroke.

2.11 Patient and family experiences of the LCP

A further aim of this study was to explore experiences of LCP use for patients, families and the multidisciplinary team. Five previous studies were identified that reported family experiences of LCP-based care, mainly in cancer settings although two papers (Veerbeek et al., 2008a; b) included a small number of stroke patients. The studies have various design limitations and generally used questionnaires for data collection. Questionnaires yield superficial information (Polit and Beck, 2008) and thus have limited ability to explore complex aspects of end-of-life care.

In the Netherlands, Veerbeek et al. (2008a) conducted a non-randomised intervention study evaluating LCP impact on reported communication and levels of bereavement in 271 participants drawn from two hospitals, three nursing homes and one primary care area. The sample comprised 131 participants whose family member died in the 15 months before the LCP was introduced (control) and 140 participants whose family member died in the first year after LCP introduction. In 14 cases (5.5%), stroke was the cause of death. Data were collected via postal questionnaires three months post-bereavement. Quality of communication was assessed using the validated Views of Informal Carers - Evaluation of Services (VOICES) questionnaire. A validated tool (Leiden Detachment Scale) was used to measure bereavement. Response rates of 59% for controls and 55% for the intervention group approached the 60% level defined as acceptable (Polit and Beck, 2008) for questionnaire surveys.

Relatives in the intervention group reported significantly lower bereavement impact ratings than controls ($p=0.01$), with no significant difference between groups in ratings of communication quality. Many relatives ($n=124$, 89%) from the LCP group reported receiving understandable information and many ($n=123$, 88%) were satisfied with their involvement in decision-making. For both LCP and non-LCP groups, fewer relatives

recruited through hospitals (n=86, 82%) reported receiving comprehensible information than did relatives recruited through nursing homes (n=102, 92%) or home care (n=44, 98%). There was little change before (n=85, 65%) and after LCP introduction (n=92, 66%) in rates of warning relatives their family member was likely to die soon.

Veerbeek et al. (2008a) was strengthened by its reasonable sample size and use of intention-to-treat analysis. Nevertheless, the use of historical controls introduces error (Cochrane Childhood Cancer Group, 2009) and undermines its validity. Changes other than the intervention, not measured by the researchers, may have occurred over time and brought about the apparent reduction in reported bereavement levels in the intervention group. Overall, many relatives appeared satisfied with decision-making and communication but information given in hospital may have been poorer than in other clinical settings. Using questionnaires limited the researchers' ability to probe how decisions were achieved or how information was shared. Further, the implication of differing diagnoses e.g. cancer, dementia or stroke for communication and decision-making were not explored.

Veerbeek et al. (2008b) reported a study in identical settings, within the same time period and with similar sample size (n=269) for relatives. While not stated, the paper appeared to report the same study as Veerbeek et al. (2008a), although the second i.e. 2008b paper focused on documentation and symptom control. Casenotes were reviewed and the relatives and 472 nurses completed questionnaires on patients' symptoms. As with Veerbeek et al. (2008a), data were collected for the time periods before and after LCP introduction. Nurses and relatives both reported lower overall mean scores for symptom burden in the intervention group ($p=0.016$). Yet the methodological weaknesses of the first paper i.e. use of historical controls and non-random sampling pertained to the second paper also. Additionally, the nurses were unblinded assessors of symptoms, another source of bias. Thus the findings suggested that the LCP was associated with reduced symptom burden but the study had methodological limitations.

The studies by Veerbeek et al. (2008a; b) relate to the research questions for this study because they included a small number of stroke patients. The studies suggested that LCP use was associated with reduced symptom burden, that LCP-based care was generally acceptable to families but that even where the LCP was used, communication in hospitals

was poorer than in other care settings. Data for all disease groups were aggregated for reporting hence it is not possible to identify stroke-specific experiences from these studies.

Mullick et al.(2009) reported a pilot survey of satisfaction with LCP-based care using a short non-validated questionnaire with 25 relatives (response rate 59%) returning to a London ward to collect death certificates after the death of a family member. The care setting was acute but the specialty was unreported. Although 21 (84%) of respondents strongly agreed or agreed that they were satisfied with communication, symptom control and family support, there was no comparison group. Further, acquiescent response bias (Gerrish and Lacey, 2010), or the tendency for participants to provide pleasing answers to questions cannot be ruled out in data collected at such a potentially sensitive time. Additionally, the small sample size limited the generalisability of findings and the use of a non-validated questionnaire may have compromised the validity of the study.

In a UK postal survey, Mayland, Williams, Addington-Hall, Cox, & Ellershaw (2013) used a validated questionnaire (ECHO-D) to compare 225 bereaved relatives' views of end-of-life cancer care quality in one hospice and one hospital (response rate 35.1%) where the LCP was used. Significantly more relatives ($p=0.02$) in the non-random sample were recruited from the hospice ($n=109$, 40.5% response) than from hospital ($n=146$, response 31.9%). Relatives of all hospice participants and a small majority of the hospital group (78, 53.4%) had been cared for using the LCP. The sample sizes required by power calculation were achieved, although these were for two groups of 100: hospice and hospital. In the event, three groups emerged: hospice, hospital-with-LCP and hospital-without-LCP. Comparisons between groups were therefore underpowered. Data for all groups were collected more than nine months after bereavement, a point at which bereaved proxies' recall of patients' symptoms is reported to diminish in severity and frequency (McPherson and Addington-Hall, 2004). Thus, levels of symptom prevalence and care quality reported in the study may be unreliable. Further, the hospital-with-LCP group were interviewed significantly earlier after bereavement (9.8 months, $p<0.0001$) than the hospital-without-LCP group (14.8 months), meaning that the hospital-with-LCP group may have had better recall.

Across the groups, relatives were informed of their family member's impending death at roughly similar rates (67.6%-76.9%). Hospice participants ($n=44$, 40.4%) were

significantly more likely to have been told what to expect when their family member died than relatives in the other two groups (16.2-28.8%, $p=0.002$). Hospice participants reported the highest levels of satisfaction with communication. Despite having LCP-based care in common, hospice relatives were more satisfied with care quality than the hospital-with-LCP relatives. In contrast, hospital-without-LCP relatives reported the lowest quality of care and highest symptom burden.

The study was strengthened by its use of a validated tool and contemporaneous controls in the form of the non-LCP hospital group. Notwithstanding, weaknesses in the study preclude useful conclusions about LCP use. First, the level of non-response in the study undermined its internal validity, as data were not collected from over 60% of the sample. Secondly, recall bias may have affected reports, particularly in the hospital-without-LCP group. Although the authors concluded that the LCP brought about improvements in care, the study design undermined this conclusion. The study was a cross-sectional survey of a non-random sample. Since correlational research cannot demonstrate causality (Parahoo, 2006), suggestions from Mayland et al. (2013) that the study demonstrated LCP effectiveness are not credible. In terms of the research question for this study, decision-making was not reported and the study did not include stroke patients.

Costantini et al. (2014a) reported a non-randomised cluster trial of LCP implementation with cancer patients in four medical wards in a Genoese hospital. As with Veerbeek et al. (2008a; b), an inherently weak quasi-experimental design was adopted, using historical controls. Face-to-face or telephone interviews were conducted with relatives four to six months post-bereavement. Of 111 eligible cases, data were compared from 46 relatives (response rate 73%) whose family member died before LCP implementation against 33 relatives (response rate 68.8%) from the post-implementation phase, using items from the validated VOICES tool to measure reported symptoms and the validated Toolkit questionnaire to measure care quality.

There were no significant differences in levels of reported symptoms before and after LCP implementation. Care quality scores reported by relatives in the LCP group were higher than in the pre-LCP group, although the improvement in overall rating of care quality was not statistically significant. Significant improvements were seen in scores for respectful care ($p=0.015$, 95% CI 3.6-30.0), family emotional support ($p<0.001$, 95% CI 9.6-32.3),

care co-ordination across services ($p=0.007$, 95% CI 4.2-24.3) and self-efficacy for families ($p=0.049$, 95% CI 0.3-28.2). However, although scores in the LCP group were higher, they fell short of complete satisfaction with care, with mean Toolkit scores (out of 100) of 73.4 for appropriate information-giving and alignment of decisions with patients' wishes. Self-efficacy or families' confidence in their ability to help the patient manage their care was rated lower, at 57.0. Family emotional support rated lowest at 51.9.

The ability of Costantini et al. (2014a) to establish effectiveness was undermined by the use of a historical control group that, as in Veerbeek et al. (2008a; b) introduced possible error. Yet, while the study was insufficiently rigorous to provide convincing evidence of LCP effectiveness it nevertheless demonstrated a trend towards improvement. Costantini et al.'s reasonable response rates mean that the questionnaire data on quality of care may provide a realistic indication of local LCP care standards. Costantini et al. (2014a) showed that relatives of patients on the LCP were only partially satisfied with their ability to help manage care. Since the study was focused on cancer patients in one Italian hospital the findings may not be generalisable to a UK stroke setting where disease trajectory and service configuration is different.

Overall, the five studies exploring family experiences of LCP-based care were limited by their poorly controlled designs and reliance on questionnaires for data collection. Only two studies included stroke patients. The impact of LCP use on patient symptom burden remained unclear. Costantini et al. (2014a) found no change, although two other studies reported lower symptom burden in patients on the LCP (Veerbeek et al., 2008b; Mayland et al., 2013). Although across the studies satisfaction with care quality was generally higher among families reporting LCP-based care, areas for improvement remained, particularly in relation to information-giving (Veerbeek et al., 2008a; Mayland et al., 2013; Costantini et al., 2014a). Additionally, satisfaction with LCP-based communication and care quality in hospitals was lower than in other care settings (Veerbeek et al., 2008a; Mayland et al., 2013). Collectively these studies strengthen the case for conducting this study, which investigated family experiences of LCP use in acute stroke care, using qualitative methods to provide a richer understanding of symptom burden, communication and care quality than that available through questionnaires.

2.12 Healthcare professionals' experiences of LCP use

Searches for this review identified eight studies that reported generally positive hospital staff perceptions of the LCP and its impact on end-of-life care, and one study that considered only negative experiences of LCP use (Di Leo et al., 2015). The positive studies are discussed first in this section, thereafter Di Leo et al. (2015) is addressed. Methods and critique for several of the studies (Di Leo et al., 2011; Thurston and Waterworth, 2012; Clark et al., 2012; Freemantle and Seymour, 2012) have been discussed already in this review. In these cases the details are not repeated here and instead cross-references are provided.

Jack et al. (2003) used two focus groups and one semi-structured interview to study the views of 15 purposively selected generalist nurses regarding LCP impact in their UK hospital. The nurses reported that using the LCP improved symptom control and communication with families while reducing unnecessary interventions and paperwork. However, problems with LCP implementation were also identified, such as occasional resistance from doctors to LCP use. The study had several features of trustworthiness (see 3.11.2). A varied sample was selected, ensuring a range of views was captured, coding and analysis were independently reviewed and member checking was undertaken. Nevertheless there were also limitations. The sample size was small and data saturation (see 3.10.1.1) was not reported. Further, all participants had an interest in palliative care and were members of the hospital palliative network, receiving extra education about palliative care and acting as links with their clinical areas. This may therefore increase the risk of a positive reporting bias.

Walker and Read (2010) undertook a phenomenological study with six ICU staff (five nurses, one doctor) in one hospital in the UK Midlands, collecting data through semistructured interviews. Participants reported that using the LCP had improved communication within teams and with families, and enabled clearer care planning and better symptom control. The LCP was described as particularly useful for nurses because it empowered them to be more confident in communication and clinical care. Walker and Read (2010) recommended that future studies should include family views of care. Nevertheless, there are methodological limitations with Walker and Read (2010). As with Jack et al. (2003), although Walker and Read's analysis was independently reviewed

thereby enhancing study rigour, their sample size was small, based in a single site, and achieving data saturation was not reported.

O'Hara (2011) reported a qualitative study with 12 nurses from oncology and elderly medicine wards in one acute hospital in England. Focus groups were used to collect data on views regarding the LCP, one with general nurses (n=6) and the other with LCP 'link' nurses (n=6). Both groups valued the LCP and its use was reported to increase trust within teams, particularly between doctors and nurses. The general nurse participants believed that using the LCP increased their confidence in communicating with families. Nevertheless, the LCP link nurse group described difficulties in commencing the LCP for patients at weekends (see 2.14.3) and both groups said a shortage of single rooms reduced privacy for patients and their families, while staff shortages limited nurses' ability to provide care. Further, general nurse participants reported a lack of ongoing education after initial LCP training. O'Hara (2011) repeated the recommendation of Walker and Read (2010) that future studies should include family views of care. O'Hara's (2011) study had limitations. At least one of the questions on the interview schedule ("Have you noticed an improvement in care for dying patients in your area?" p20) was leading. Further, as with Jack et al. (2003) and Walker and Read (2010), the small localised sample in O'Hara (2011) limited the transferability of findings.

The methods used by Di Leo et al. (2011) are reported and critiqued in section 2.10.2. In summary, Di Leo et al. (2011) reported a small Italian qualitative study of generalist healthcare professionals' views of the LCP. Participants said that using the LCP led to better symptom control, with more frequent withdrawal of unnecessary interventions. It was reported that LCP use resulted in improved communication and trust within the team, and doctors reported increased appreciation of nurses' symptom management skills. Yet time and workload constraints, often arising from understaffing, meant nurses had insufficient time to spend with dying patients and their families. As with O'Hara (2011), infrastructure limitations in terms of room space often reduced privacy for patients and their families. However, as with Jack et al. (2003), Walker and Read (2010) and O'Hara (2011), the trustworthiness of Di Leo et al.'s (2011) findings were limited by their use of a small sample from one geographical location with no report of data saturation.

From a qualitative study of 15 New Zealand nurses and nurse managers in an acute hospital using the LCP, Thurston and Waterworth (2012) also reported generally positive nurse views regarding the LCP. The participating nurses, particularly those who were newly qualified, reported improved knowledge of end-of-life care and enhanced ability to manage symptoms. Improvements in communication were also reported. The methods used by Thurston and Waterworth (2012) are reported in more detail and critiqued in section 2.10.4. In summary, it was a small single site study with limited transferability.

Clark et al. (2012) reported a mixed methods study involving a survey (n=41, response rate 18%) and focus groups with healthcare professionals (n=18) using the LCP in an acute hospital in New Zealand. As with the other studies reported in this section, views of the LCP were generally positive, with respondents reporting that goals of care were clearer with the LCP, staff had better knowledge about end-of-life care and that anticipatory prescribing had improved. Improvements in communication were also described and these are reported, with more detail on methods and critique in section 2.10.4. As with O'Hara (2011) and Di Leo et al. (2011), time and workload constraints, difficulties at weekends and inadequate infrastructure were reported as barriers to the provision of good quality end-of-life care. Participants also reported lack of ongoing education after initial LCP training, which was consistent with findings from O'Hara (2011). In summary, Clark et al. (2012) was a small single site study with limited transferability and with internal validity that was weakened by a low survey response rate.

Freemantle and Seymour (2012) reported a qualitative interview study with 11 UK healthcare professionals using the LCP in one hospital's oncology wards. Although difficulties in recognising dying and decision-making were reported (see 2.10.4), participants believed using that the LCP made it easier for them to withdraw unnecessary interventions such as vital signs monitoring, that using the LCP helped standardise good quality end-of-life care for all patients and that anticipatory prescribing was improved, thereby ensuring timely management of symptoms. Freemantle and Seymour's (2012) study methods are critically reported in more detail in section 2.10.4. To summarise, the study had limited transferability because it used a small sample in one geographical location.

Sleeman et al. (2015) reported findings from semistructured interviews with 25 nurses, doctors and allied health professionals working in ICU in one London hospital. Data were collected in 2009 i.e. before the LCP was withdrawn in the UK. Using the LCP was said to be particularly helpful for junior staff by clarifying care processes and improving the consistency of care. Additionally, the presence of LCP paperwork in casenotes possessed a symbolic value in signalling to staff a shift in care focus. Nevertheless, concerns were expressed that the paperwork encouraged reductionist box-ticking and inhibited use of professional judgement. As with other studies, limited education in end-of-life care was reported. One participant discussed the LCP's limited evidence base. The study's trustworthiness was enhanced by using a maximum variation sample, independent review of the thematic analysis and by consideration of negative cases. Nevertheless participants had varying levels of familiarity with the LCP as it was not used regularly in ICU. This unfamiliarity with the topic under investigation may limit the credibility of the study. Additionally, data saturation was not reported and the sample was drawn from a single site, further limiting credibility and transferability.

One qualitative study (Di Leo et al., 2015) explored only negative views of the LCP. The study was nested within the Italian cluster trial of the LCP (Costantini et al., 2014b) (see 2.7). Di Leo et al. (2015) recruited staff from six intervention wards across six of the eight hospitals in the cluster trial. Semistructured interviews were conducted with six doctors and five nurses who during the trial either expressed negativity about the LCP or did not comply fully with LCP implementation. Participants reported that employment turnover resulted in some staff missing LCP training and consequently lacking competence in LCP use. Participants also criticised the LCP criteria for recognising dying and believed that the LCP was reductionist, with a focus on completing the documentation rather than a focus on patients. Infrastructure limitations and lack of time were said to hamper holding conversations with families and patients as the LCP directed. Di Leo et al. (2015) used methods that enhanced credibility. Thematic analysis was agreed between two researchers and data saturation was reported. Further, the use of a sample from multiple sites strengthened the transferability of findings.

Overall findings from the studies discussed in this section must be treated with caution. Sample sizes were relatively small, ranging from six (Walker and Read, 2010) to 25 (Sleeman et al., 2015). Only one study (Di Leo et al., 2015) reported reaching data

saturation, an accepted indicator that a study has answered its research question and therefore has credibility i.e. validity (Lincoln and Guba, 1985). The generally positive studies were each conducted in single hospitals, limiting the transferability of any credible findings although di Leo et al. (2015) has greater transferability.

Nevertheless most of the studies, although individually weak, have a general overall trend i.e. the participating healthcare professionals believed that using the LCP was beneficial for care quality, decision-making and communication. Two studies (Sleeman et al., 2015; di Leo et al., 2015), published after LCP withdrawal in the UK, both reported inadequate education provision and a lack of individualised care afforded by the LCP model. The lack of training in LCP use is consistent with findings from repeated reviews of UK healthcare (see 2.8.5).

Yet these studies did not investigate stroke care and did not explore how healthcare professionals decided to use the LCP. Therefore recognising dying in acute stroke and related decisions to use the LCP were confirmed as issues for further study.

2.13 Preferred place of end-of-life care after stroke

In Scotland, although place of death i.e. hospital or usual place of residence, is measured as an indicator of care quality (Health Improvement Scotland, 2013), searches for this review did not identify any studies reporting how many patients from Scottish stroke units move to another setting for end-of-life care.

The qualitative study (Payne et al., 2010) of 28 stroke patients and their relatives (n=25) in two acute stroke units in England (see 2.10.3) showed that patient and family preferences for place of care were not explored by stroke unit staff. No patients or families were offered the choice of discharge for end-of-life care in another setting.

Similar findings were reported in critical care by Coombs, Long-Suthehall, Darlington and Richardson (2014). They investigated the discharge of patients from ICU for end-of-life care at home using focus groups (49 participants) and telephone interviews (21 participants) with a UK-wide sample of ICU nurses, consultants, GPs and service users. Participants supported the concept of discharging dying patients home but worried about transferring unstable patients, having insufficient time to transfer before the patient died,

and insufficient resources for transfer and for care in the community. Health professionals reported that in their experience few ICU patients were ever transferred home to die and transfer was not commonly offered to patients and families. The relatively large number of participants, inclusion of service users and reports of data saturation enhanced the study's credibility and its transferability was strengthened by the use of a UK-wide sample.

Coombs et al. (2014) highlight the dearth of evidence regarding community infrastructure and the experiences of patients discharged for end-of-life care. This study sought to contribute evidence on the topic from a stroke perspective.

2.14 Challenges in end-of-life care after stroke

Literature relating to the research questions has been reviewed and a case made for undertaking this study. Nonetheless, some additional stroke-related issues emerged during the study and pertinent literature is reviewed in the following sections. First, the prevalence of symptoms in end-of-life stroke care is evaluated and the involvement of specialist palliative services discussed. Thereafter literature relating to weekend end-of-life care is introduced and information-giving after stroke is reviewed.

2.14.1 Symptom burden and specialist palliative care in acute stroke

Mazzocato, Michel-Nemitz, Anwar and Michel (2010) retrospectively reviewed records in one Swiss hospital for 42 stroke patients referred to a specialist palliative care service. Referred patients constituted 26% (n=37) of the 142 deaths occurring in the referring stroke unit during the study period. Dyspnoea (81%, n=34) and pain (69%, n=29) were the most common symptoms. Dry mouth (62%), constipation (38%), anxiety (26%) and delirium (14%) were also reported. Communication problems were almost universal; only three patients (7%) could communicate normally on admission, with the remaining 93% affected increasingly by aphasia and decreasing conscious level in the days leading up to death.

In Mazzocato et al. (2010), only a quarter of stroke patients who died in the hospital during the study were reviewed. Hence symptom patterns in the majority of dying stroke patients

were not reported. Additionally, although reporting that symptoms were managed with drugs in the last 48 hours of life, Mazzocato et al. (2010) did not specify whether any end-of-life care pathway was used to manage care. The incidence of dysphagia or feeding difficulties was not reported.

In the US, Holloway et al. (2010) conducted retrospective analysis of hospital database information for 101 stroke patients (6.5% of total stroke admissions) referred to inpatient palliative care services in one hospital from 2005-2007. Data for stroke patients were compared with data for patients referred to specialist palliative care services with other conditions. Pain and dyspnoea were the most common symptoms for stroke patients. Referred stroke patients had greater functional impairment, were more likely to die in hospital, were more likely to be referred for support with end-of-life decision-making yet had lower symptom burden than patients with heart failure, chronic obstructive pulmonary disease (COPD) or dementia ($p < 0.05$ for all variables). One third of all stroke referrals were for support with decision-making.

Although there appear to be differences between the studies in identified symptom burden, Holloway et al. (2010) cannot be compared with Mazzocato et al. (2010) because the two patient groups were dissimilar. Over one third ($n=39$, 38.6%) of patients reviewed by Holloway et al. (2010) were receiving mechanical ventilation and thus were likely to be sedated, which may account for the apparently lower incidence of symptoms than in other disease groups. Further Holloway et al. (2010) included patients with subarachnoid haemorrhage, which is reported as having a different trajectory and management from that of primary intracranial haemorrhage (Nilsson et al., 2000). Nevertheless, like the Swiss study, Holloway et al. (2010) did not report if an end-of-life care pathway was used for stroke patients whose symptoms they reviewed.

In summary, symptoms such as pain and dyspnoea were commonly reported in stroke patients referred to specialist palliative services. Symptoms in the wider end-of-life stroke population were not reported by Mazzocato et al. (2010) or Holloway et al. (2010) and neither was the use of an end-of-life care pathway. Therefore this study explored symptom burden in stroke patients at the end-of-life, with and without end-of-life care pathway use.

2.14.2 Referral rates to specialist palliative care services

Several studies have shown wide international variations in referral rates to specialist palliative care services for acute stroke patients at the end of life. Reported rates are now considered country by country.

As outlined in 2.14.1, the Swiss study by Mazzocato et al. (2010) reported 42 referrals out of 142 stroke deaths (29.6%) over a five year period. By contrast in the US Holloway et al. (2010) reported 101 referrals out of 1551 stroke admissions (6.5%) over a three year period.

In Australia, Le, Pisasale and Watt (2008) reported 42 specialist palliative care referrals out of 210 admissions (20%) in six months to one urban stroke service. Referrals were made to obtain advice and support with symptom management and deciding complex issues such as clinically assisted nutrition and hydration. A more recent Australian retrospective audit (Eastman et al., 2013) found that 62 (11.4%) of 544 patients admitted to an acute stroke unit in one year were referred to specialist palliative care services. Of the 87 patients who died in the stroke unit during their admission, 49 (56.3%) were seen by specialist palliative care staff. Referred patients tended to be older, have more pre-stroke disability and had a longer trajectory from stroke unit admission to death (median 6 days, IQR 3-12) than patients who died without referral (median 2.5 days, IQR 1-7.5, $p=0.002$). Eastman et al's study (2013) was conducted prior to the planned introduction of an end-of-life care pathway to the stroke unit, so the effect of pathway use is not reported.

Varying referral rates have been reported in the UK. Payne et al. (2010) reported a purposive sample of 28 patients out of 191 stroke admissions to a UK stroke service over a nine month period, of which some received end-of-life care (see 2.10.3). No patients were referred to specialist palliative care. However, this was a qualitative study. Measuring referral rates was not a primary aim and the lack of referrals was an incidental observation. These findings are echoed in a conference abstract (Jeffries, Shipman and Wee, 2012) reporting semistructured interviews with UK stroke healthcare professionals ($n=15$) where input from specialist palliative care services was generally perceived as irrelevant to end-of-life care after acute stroke. Staff would only seek help from specialists where symptom management or ethical decisions were complex or where patients had cancer as well as

stroke. Since the detail of a full paper is not available, it is difficult to evaluate the trustworthiness of these findings.

Conversely Adams et al. (2013) reported that during a nine month period in one English acute stroke unit, 29 (58%) patients out of 53 who died received specialist palliative input. The unit used the LCP and 20 of the 29 patients referred were reviewed by a specialist nurse after the LCP was commenced. However, this was reported in a conference abstract and the precise nature of the specialist input is not reported (see 2.9.3).

2.14.2.1 Specialist palliative care - summary

In summary, dyspnoea and pain are reported as common symptoms among patients referred to specialist palliative care services from acute stroke settings. However, referral rates vary widely and in the studies identified for this review, at least half of patients dying after acute stroke were not seen by specialist services. Referrals were commonly made in order to seek support with decision-making or manage complex symptoms. There was no evidence of LCP impact on symptom prevalence among dying stroke patients. It was not reported how the use of an end-of-life care pathway, such as the LCP, designed to address common symptoms, might meet the needs of dying stroke patients and their families.

2.14.3 Weekends and end-of-life care

In this study, weekends emerged as a consideration in end-of-life decision-making. Some of the studies included in this review reported issues affecting end-of-life care at weekends and these are now discussed.

In a study by O'Hara (2011), LCP 'link' nurses reported that clearly documenting medical care plans clearly in advance of weekends avoided delay in implementing the LCP during weekends, when LCP use became necessary. However, O'Hara's study (see 2.12) was small (n=12), localised to nurses in one acute hospital in England, and qualitative. The effectiveness of documenting weekend contingency plans was not demonstrated quantitatively or conclusively.

Problems with deciding LCP use at weekends have been reported in multiple care settings. In New Zealand acute hospital wards, Clark et al. (2012) (see 2.10.4) reported that medical

teams covering weekends were reluctant to commence the LCP for patients not well known to them. Freemantle and Seymour (2012) reported that in one English hospital fewer cancer patients were commenced on the LCP at weekends. Their semistructured interviews (see 2.10.4) with nurses (n=7) and doctors (n=4) involved in the care of six patients who died revealed that time and availability of senior doctors was considered key to LCP decision-making. When there was insufficient time for senior clinicians to assess patients comprehensively, as at weekends when fewer senior staff were available, LCP implementation would not occur.

In the UK, Pollock, Caswell, Porock and Harwood (2013) conducted an ethnographic study using overt non-participant observation, casenote review and semistructured interviews with staff (n=38) and relatives (n=13) in four elderly care wards in one UK acute hospital. The LCP was used in the care of 31 of the 42 patients studied. The lack of senior medical cover in wards at weekends, overnight and during public holidays was observed to delay decisions to use the LCP. Delayed LCP decisions sometimes delayed analgesia prescriptions, resulting in distress for patients.

In short, deciding LCP use in cancer care, medical units and care of the elderly specialties could be delayed at weekends. Prior to this study, the situation relating to weekend care of the dying in acute stroke care was unreported.

2.14.4 Information-giving after stroke

The manner in which information was shared with families emerged as an issue in this study and relevant literature is now considered.

From a systematic review on family involvement in end-of-life decision-making, Meeker and Jezewski (2005) recommended that clinicians should anticipate the information that families might need and provide information proactively. Meeker and Jezewski (2005) reviewed 51 English language studies looking at family experiences of decision-making in end-of-life care and their associated needs. Five databases including Cochrane were searched and qualitative and quantitative studies were included. Findings indicated that in end-of-life situations families wanted the maximum information available. However, this review was not specific to stroke care. Similarly although some existing studies of LCP use

such as Veerbeek et al. (2008) and Costantini et al. (2014a) reported on relatives' satisfaction with information received (see 2.11), they did not investigate mechanisms for exchanging information and did not focus on stroke care.

There is some evidence that even where patients survive, relatives feel the greatest need for information in the immediate aftermath of stroke. In a Swedish study Wallengren, Segesten and Friberg (2010) used longitudinal qualitative interviews (at four weeks and six months) to explore the information needs and information-seeking behaviours of 16 relatives nominated by stroke survivors from two stroke units. The relatives wanted information tailored to their family member's symptoms and at four weeks post-stroke the sample fell into two groups regarding information-seeking. One group were not satisfied with any information they were given, whether written or spoken. The other group actively found and used a range of information sources. These included the internet, newspapers, magazines, health professionals or social networks such as friends or stroke groups. Information-seeking behaviours diminished over time and by six months the relatives reported relying on their own knowledge and experience. Four patients died during the study and their relatives were subsequently excluded. Therefore information needs or information-seeking behaviours relating to end-of-life care were not reported.

In their study of UK end-of-life stroke care Payne et al. (2010) (see 2.10.3) reported that relatives seldom sought information online but valued interaction with healthcare professionals. The relationship with staff who gave information was more prominent in reports than the quality of information shared and style of communication mattered more than content. Families welcomed opportunities to speak with staff, and were dissatisfied where such chances were not available. Relatives wanted candour about prognosis, including the possibility of fatal outcome. It was not reported if the LCP was used in the stroke units studied, hence its effect on communication in end-of-life stroke care could not be understood.

Forster et al. (2012) conducted a Cochrane systematic review to compare passive and active information-giving interventions. They searched 10 publications databases and four trial registers, identifying 21 studies for comparison. Passive methods were defined as single episodes of information-giving with no follow-up. Active information-giving was an ongoing process of engagement to allow patients or carers to consolidate knowledge and

engage with the stroke team by asking questions or acquire coping skills. Outcome measures included patient or carer knowledge, mood and satisfaction. Although active information-giving significantly improved patient ($p=0.001$, 95% CI 0.12 to 0.46) and carer knowledge ($p=0.03$, 95% CI 0.06 to 1.43) and patient satisfaction ($p=0.001$, 95% CI 1.33 to 3.23) and reduced patient depression scores ($p=0.01$, 95% CI -0.93 to -0.10), no effect was seen on carer mood or satisfaction. There were insufficient data to examine the effect of information-giving on carers' psychological distress. Thus active methods of information provision appeared to be of some benefit, although more for patients than carers. However, Forster et al.'s (2012) review looked at stroke rehabilitation information rather than end-of-life information.

LCP documentation included a written leaflet given to families when LCP use began (see Appendix 1). This could be argued as fitting with Forster et al.'s (2012) definition of passive information-giving. Yet the LCP model also required staff to interact with families and patients every few hours, providing information and answering questions. This may fit with the active style of information-giving defined by Forster et al. (2012). Although Forster et al. (2012) did not identify that actively providing rehabilitation information was of significant psychological benefit for family carers, the communication relating to dying was not explored. Therefore this study considered communication styles used by healthcare professionals in providing end-of-life information to patients and families.

2.15 The LCP and the media

By the time this study began in 2011, isolated UK newspaper items had begun to emerge criticising the LCP. These ranged from a broadsheet newspaper letter from academics and clinicians expressing concerns about misdiagnosis of dying, withdrawal of food and fluids and a 'tick-box' attitude to care, all associated with LCP use (Millard et al., 2009) to tabloid stories of over-sedation and euthanasia (Mackinnon, 2011). In summer 2012 i.e. towards the end of data collection and analysis for this study, the level of media coverage increased rapidly after a Kent neurosurgeon, Patrick Pullicino, presented at the Royal Society of Medicine, recounting an anecdote from his clinical practice where he considered junior staff had commenced a patient on the LCP inappropriately, and concluding that the LCP was being used to hasten death in many elderly patients to free NHS beds (source:

Pullicino, personal correspondence with researcher, 2012). His presentation was reported by a UK tabloid newspaper (Doughty, 2012a).

Thereafter came a slew of newspaper articles describing instances where the LCP was used without informing patients' families (Stanford, 2012), families reported that their relative was starved or deprived of fluids (Rawstorne, 2012) or that patients survived despite LCP use and were discharged from hospital (Stevens, 2012). One family complained to police that hospital staff attempted to murder their relative by using the LCP (Smith, 2012). Not surprisingly, parliamentary questions and debate ensued (Hansard Lords, 2012b; a; Hansard Commons debates, 2013).

Despite a consensus statement from UK stakeholder organisations endorsing the appropriate use of the LCP and emphasising that the LCP was not a substitute for clinical judgement (Age UK et al., 2012), the media storm did not abate. Newspaper opinion columns weighed in (Phillips, 2012a; b) and concern was expressed that in England, rates of LCP use were being used as financial incentives for hospital trusts (Laurance, 2013). In peer-reviewed journals too, the issue was hotly debated (Murray, 2012; O'Dowd, 2012; Brewer, 2012; Laing, 2012; McCartney, 2012; Farrell, 2012). The BMJ issued an open letter criticising tabloid coverage as misrepresentative (Kmietowicz, 2012) and a few voices were raised calling for moderation (Greenhalgh, 2012; Palmer, 2012).

The Scottish Government (2012) issued a position statement indicating that the LCP could remain in use, that decisions to use the LCP should include the wider care team and families but that ultimate responsibility rested with the most senior doctor available. Decisions taken by out-of-hours teams to use the LCP should be countersigned by patients' own doctors as soon as possible. The statement also emphasised that using the LCP did not preclude the provision of clinically assisted hydration or nutrition. Hence this was the Scottish policy context in relation to LCP use during the data collection period of this study.

An independent chair, Baroness Neuberger, was appointed to oversee and amalgamate three separate reviews of the LCP undertaken by the Association of Palliative Medicine, the Dying Matters Coalition and the National End of Life Care Programme (Department of Health, 2013).

2.15.1 The Neuberger Report

The Neuberger review was conducted by a panel of ten professional and lay members. The panel members reviewed written submissions from members of the public, 91 healthcare professionals with LCP experience, 36 professional bodies and other organisations. The panel also drew on Parry et al.'s (2013) rapid evidence assessment (see 2.7), a review of hospital complaints, two surveys of healthcare professionals and oral evidence from 113 members of the public across four public panel sessions. The scope of the review was limited to England although Parry et al. (2013) included international literature and contacted principle investigators of ongoing studies, including this study. However, Parry et al. (2013) published before this study ended, hence the findings of this study could not be included.

Neuberger et al. (2013) found that the LCP reflected principles of good quality, ethical end-of-life care. They acknowledged that the LCP contributed to timely clinical decisions and heard testimony of peaceful and dignified deaths where the LCP was used. Nevertheless the panel found that Parry et al. (2013) highlighted the weak evidence base for the LCP despite its widespread use. Further, Neuberger et al. (2013) identified instances of:

- Poor communication resulting in relatives being unaware of changes in treatment and care including morphine use or that patients were dying
- Mistakes with documentation and poor record keeping
- Inadequate provision of nutrition and hydration. The panel found that these were often withheld, contrary to LCP guidance
- Inadequate training in end-of-life care.

Additionally Neuberger et al. (2013) acknowledged the difficulties healthcare professionals encountered in recognising dying and judging when to commence the LCP. There was insufficient training in LCP use. Infrastructure limitations were also reported, with a lack of private spaces for staff to speak with patients and families.

Neuberger et al. (2013) reported that many of the identified problems related to clinicians' insufficient knowledge of current guidelines on end-of-life care and their reluctance to discuss dying and associated uncertainties with patients and their families. Neuberger et al. (2013) concluded that standardised protocols such as the LCP were not the best solution to the situation. The panel recommended that the LCP be phased out over the following year and be replaced by individualised care plans that drew on good-practice guidelines specific to separate conditions.

2.15.2 Neuberger: responses and implications for this study

Neuberger et al.'s report was criticised (Regnard, 2013; Wrigley, 2014) as internally inconsistent i.e. failing to find evidence that the LCP caused the poor care, yet recommending the LCP be withdrawn. Regnard (2013) argued that poor care was caused not by LCP *per se*, but by the problems historically associated with end-of-life care such as poor care standards, inadequate communication and lack of education. The decision to withdraw the LCP, Regnard (2013) suggested, was political, designed to appease critics and akin to abandoning the UK Highway Code because of poor performance by some drivers. Further, Regnard (2013) argued that the decision lacked foresight because the tool was withdrawn before an adequate replacement was available. Wrigley (2014) suggested that rather than recommending the withdrawal of the LCP, attention should have been focused on increasing education and training in end-of-life care and decision-making.

Nevertheless, interim guidance was issued in England and Scotland (NHS England, 2013; Scottish Government, 2013) directing the withdrawal of the LCP and outlining substitute principles of care. LCP withdrawal began in England from July 2013 and in Scotland from December 2013, i.e. six to 12 months after data collection ended for this study. Formal new guidelines on end-of-life care followed (National Institute for Health and Care Excellence, 2015; NHS Scotland, 2015). The new policies recommended that end-of-life care should be individualised while drawing on key principles such as good communication, shared decision-making and appropriate pharmacological interventions. Thus UK end-of-life health care policy shifted from previous recommendations, outlined in 2.8.2, which endorsed standardised clinical tools such as the LCP.

This study explored some of the clinical problems identified by Neuberger et al. (2013) i.e. recognising dying, LCP decision-making including family involvement and family experiences of LCP-based care. Thus the findings of Neuberger et al. (2013) confirmed that this study's research questions were relevant to clinical practice where the LCP was used.

Further, the House of Commons Health Committee (2015) noted five priorities for UK end-of-life care following withdrawal of the LCP. The priorities centred on the clear communication of the recognition of dying, sensitive communication, patient and family involvement in decisions, family support, and care planning that includes nutrition and hydration. Thus although the LCP was withdrawn, the research questions in this study remain relevant to end-of-life care in the UK.

Finally, because the LCP was withdrawn shortly after data collection for this study ended, the study became a unique opportunity to explore the use of the LCP before it disappeared from UK end-of-life care.

2.16 Summary of key points arising from the literature

The findings and methodological quality of existing studies of end-of-life care pathways were reviewed and their relevance to stroke care was considered. The review was also used to justify this study and to identify suitable research methods. Key points are now considered.

There is a substantial requirement worldwide for end-of-life care after stroke. When this study commenced, the UK and Scottish governments recommended the use of end-of-life care pathways such as the LCP for patients dying in all clinical areas, although the evidence base for the LCP was limited. Problems with end-of-life care quality have been reported by several UK bodies. These include poor communication, inadequate physical care, infrastructure limitations and insufficient training, including training to use the LCP. There is some evidence that in the UK, the public and some healthcare professionals find conversations about dying to be uncomfortable, even where the LCP was used.

Recognising that patients are dying is identified in the literature as the necessary precursor to deciding end-of-life care. Yet recognising dying is reported to be clinically challenging, particularly in stroke settings. Although some clinical features of stroke are recognised as predictors of early mortality in large cohorts, these cannot be used for prognostication with individuals. Although clinical judgements used by generalist healthcare professionals to recognise dying have been reported, no studies identified for this review explored judgements used by stroke clinicians. Further, the role of relatives in recognising dying is not reported. The criteria for recognising dying included in most versions of the LCP have been criticised as inapplicable in acute stroke. The criteria used to decide end-of-life care pathway use in stroke units were unknown prior to this study.

National and local clinical audits show that the LCP was not used for all patients who died but none report reasons for non-use. Only one study specifically investigated the clinical decision to use the LCP. The study was conducted in cancer care and families were not included. Owing to the incapacitating nature of severe stroke, family views of patient preferences are often required in shared care decisions. Families may experience discomfort with their role of proxy informant and family views have been reported to influence departures from normative healthcare practice. This review identified no studies investigating decisions to use the LCP in stroke care.

Only two studies of patient and family experiences of LCP-based care included stroke patients. Families reported higher satisfaction with LCP-based care than non-LCP care for dying relatives but satisfaction with information-giving was generally rated lower than other aspects of care. Hospital-based care received poorer ratings than care given in hospices or the primary sector. Studies of patient and family experiences relied almost exclusively on questionnaire data, limiting the ability to probe. Hence this study used qualitative interviews with families to explore their experiences. After this study finished, Neuberger et al. (2013) reported deficiencies in LCP use in England.

Studies exploring healthcare professionals' experiences reported positive views that using the LCP in hospitals improved care and communication. However, none explored how decisions to use the LCP were made. Almost all used qualitative methods. Therefore this study, in addition to exploring decision-making and experiences qualitatively, also used

quantitative casenote data to investigate patient variables associated with decisions to use the LCP.

The Scottish Government (2008) recommends that patient and carer preferences regarding place of care at the end-of-life should be elicited. Further, place of death is measured as an indicator of care quality in Scotland (Health Improvement Scotland, 2013). Yet only one stroke care study care addressed preferences for place of care, reporting that no patients were offered the choice of discharge home for end-of-life care.

To conclude, prior to this study there was weak evidence to support the use of end-of-life care pathways such as the LCP in stroke care and little indication as to when such use should begin. There was a dearth of literature on decision-making in end-of-life care following stroke. The impact on patient care and on families of using end-of-life care pathways in acute stroke settings was unknown, and outcomes were not reported. The relationships between dying trajectories and use of end-of-life care pathways were yet to be explored.

The literature reviewed indicated that a mixed methods approach would be suitable for this study and patients, families and healthcare professionals should be involved. Therefore the research aims and questions were confirmed. The research questions were:

1. Are patients with fatal stroke who are judged to require an end-of-life care pathway different (in terms of age, gender, stroke type/severity or comorbidity) from patients with fatal stroke who die without introduction of an end-of-life care pathway?
2. What are family and health-care workers perceptions of using an end-of-life care pathway for patients who die after acute stroke?
 - 2a. How is the clinical decision made to place a stroke patient on an end-of-life care pathway?
 - 2b. What is the experience of end-of-life care pathway use for stroke patients, families and the multidisciplinary team?

3. What is the outcome for stroke patients on an end-of-life care pathway transferred from stroke unit to another care facility?

In the next chapter, literature pertaining to the methods is reviewed.

Chapter 3 - Literature pertaining to the methods

3.1 Research questions

1. Are patients with fatal stroke who are judged to require an end-of-life care pathway different (in terms of age, gender, stroke type/severity or comorbidity) from patients with fatal stroke who die without introduction of an end-of-life care pathway?
2. What are family and health-care workers perceptions of using an end-of-life care pathway for patients who die after acute stroke?
 - 2a. How is the clinical decision made to place a stroke patient on an end-of life care pathway?
 - 2b. What is the experience of end-of-life care pathway use for stroke patients, families and the multidisciplinary team?
3. What is the outcome for stroke patients on an end-of-life care pathway transferred from stroke unit to another care facility?

3.2 Statement of methods

Mixed methods were used to answer the research questions in this study. A quantitative casenote review was used to investigate differences between patient groups and outcomes, answering the first and third research questions. The second question relating to perceptions, decision-making and experiences was explored using a qualitative approach that incorporated principles of modified grounded theory, with semi-structured interview as the main data collection method, complemented by a quantitative questionnaire. In this chapter, the philosophical stance of the researcher is presented and the influence of this stance on the use of mixed methods is described. Challenges of researching end-of-life care and the use of multiple study sites are then considered. Thereafter, the quantitative design, sample, data collection methods and analysis are reviewed, before the use of a grounded theory approach to qualitative sampling, data collection and analysis is discussed. The use of a valid and reliable questionnaire in conjunction with qualitative interviews is also

considered. Issues affecting qualitative and quantitative rigour are then reviewed. Finally, ethical aspects of the study are considered.

3.3 The research approach

The research adopted a pragmatic stance that combined the quantitative and qualitative research paradigms. Morgan (2007) suggests that the term ‘paradigm’ is used variably. First, the term may refer to a complete, but vague, worldview. Second, the term may refer to epistemological stances i.e. how we understand or investigate the world. Third, the term may be used for beliefs about meanings and ways of operating that are shared within disciplinary communities. In this thesis, the term ‘paradigm’ is used in the disciplinary sense, referring to shared beliefs about research procedures within the health and social science disciplines.

Malterud (2001) argues that in health research, theoretical underpinnings should be used not as ends in themselves, but to achieve the goal of knowledge generation. A congruent argument is suggested by Johnson & Onwuegbuzie (2004), who identify pragmatism as a third paradigm. Researchers working in a pragmatic paradigm, argue Johnson & Onwuegbuzie (2004), choose their methods to suit the research question, not their ontological persuasion. Further, according to Johnson & Onwuegbuzie (2004), researchers working within a pragmatic paradigm value outcomes, such as improving health care processes, over their own philosophical framework.

Adopting a pragmatic approach to research has been criticised. Some researchers maintain that the quantitative and qualitative paradigms are mutually exclusive (Polit and Beck, 2004). However, Avis (2005) argues for a middle ground in social research, where it is accepted that some events and processes are socially constructed i.e. subject to participants’ varied perspectives, while also being empirically measurable by researchers. Bryman (2012) alludes to disagreements within the research community regarding paradigms, with some researchers holding that paradigms are epistemological positions, and are consequently fixed and not interchangeable. Nevertheless Bryman (2012) suggests that major disagreements about paradigms are now over, with an increasing acceptance of pragmatism in research.

Taking these arguments into consideration, this research study adopted a pragmatic stance combining quantitative and qualitative paradigms.

3.4 Use of quantitative methods in this study

In this study, some aspects of end-of-life decision-making were measured quantitatively. Quantitative research methods are commonly employed to measure phenomena objectively using empirical observations and statistical analyses (Polit and Beck, 2008). Generalisability of findings to a wider population is also a key feature, requiring large, representative samples.

Yet quantitative research methods have been criticised as lacking depth and ability to explore sensitive issues (Gerrish and Lacey, 2010). Parahoo (2006) also emphasised the reductionist nature of quantitative research in comparison with the holistic view afforded by many qualitative approaches.

Nevertheless many authors agree that quantitative research has several strengths. Bryman (2012) cites the capacity for hypothesis testing and the generalisability of findings. Quantitative research may also be quicker and cheaper than qualitative work (Polit and Beck, 2008) and is said to enable objective statements of fact (Bryman, 2012).

Taking these arguments into consideration, quantitative inquiry was chosen as the investigative approach to the first and third research questions in this study. Using quantitative methods would allow the researcher to:

- Explore variables associated with commencing end-of-life care pathway use
- Explore outcomes of end-of-life care pathway use
- Obtain casenote data about decision-making.

3.5 Use of qualitative methods in this study

Qualitative research encompasses a group of approaches where words tend to be studied rather than numbers, theory is generated rather than tested and researchers attempt to understand human experiences by studying participants' perspectives (Bryman, 2012; Polit and Beck, 2008). Since its emergence in the postmodern era, qualitative research has been

criticised by some as lacking the strengths of quantitative research. For example, qualitative research is said to be more expensive to conduct than quantitative research because of its typically lengthy data collection and analysis timeframes (Morse and Field, 1996). Additionally, Teddlie and Tashakkori (2009) report the historical view that only quantitative research could explore or establish causality. Further, Harding & Seefeldt (2013) acknowledge that qualitative research samples rarely represent wider study populations and consequently findings lack generalisability.

Nevertheless, benefits peculiar to qualitative research have been reported. Lincoln and Guba (1985) suggest the aim in qualitative research is not to prove universal laws or theories but to understand what occurs in specific areas. Thus although samples are small the data yielded by qualitative inquiry tends to be rich and deep (Bryman, 2012) and hence is well-suited to exploring individual experiences and contexts of health care (Gerrish and Lacey, 2010). Further, recent authors (Bryman, 2012; Maxwell, 2008; Polit and Beck, 2008) accept that investigating poorly understood areas using qualitative methods may produce testable hypotheses. Additionally, some qualitative data collection techniques are well-suited for investigating difficult or sensitive topics like bereavement because of the personal interaction they afford between researcher and participant (Ritchie, Lewis, Nicholls and Ormston, 2013b). There is also agreement (Harding and Seefeldt, 2013; Bryman, 2012; Maxwell, 2008; Shaw, 1993) that qualitative inquiry is useful for investigating processes and mechanisms, such as those involved in making healthcare decisions.

After considering these arguments, qualitative inquiry was chosen as the main investigative approach to the second research question. This was because the question concerned perceptions and experiences of a healthcare intervention and the process of decision-making, both areas accepted as suitable for a qualitative approach. Further, the topic was sensitive and not well-explored, again a rationale for selecting qualitative methods of investigation.

The concurrent use of quantitative and qualitative approaches i.e. mixed methods research is now addressed.

3.6 Justification for using mixed methods in this study

Maxwell (2008) suggested the choice of qualitative or quantitative methods should be dictated by the research question, while mixed methods research involves the use of qualitative and quantitative approaches in one study (Johnson & Onwuegbuzie, 2004). Given that the research questions in this study were varied, a mix of methods was used to address them. In this study, variances between groups (pathway versus no pathway, discharge versus no discharge) were investigated quantitatively. At the same time, decision-making processes, individual experiences and perspectives were explored qualitatively.

Although the philosophy of mixed methods has been debated, their use is now increasingly common in health care research (Gelling, 2014). Bryman (2012) articulates two historical arguments against mixed methods. The first is the debate regarding incommensurable paradigms discussed in 3.3. The second argument relates to methods, and holds that particular methods belong strictly with their associated worldviews. Taken together, Bryman (2012) suggests the *sequitur* from these arguments is that using particular methods commits the user to associated ontological or epistemological position. Bryman (2012) echoes Sandelowski (2000) in agreeing that researchers have become increasingly pragmatic, accepting methods as tools that are separable from the worldviews of their users. Hence using mixed methods in this study was compatible with the pragmatic stance of the researcher.

Denzin (2009) suggests that the strength of mixed methods research is that it combines the advantages of qualitative research i.e. rich, detailed data with those of quantitative research i.e. large, representative samples that enables generalisation of findings. Nevertheless Simons & Lathlean (2010) caution that using mixed methods does not suit every research question, requires a wide range of research skills, often entails a research team and may involve logistical difficulties. Yet there is agreement (Simons and Lathlean, 2010; O’Cathain, Murphy and Nicholl, 2010; Kettles, Creswell and Zhang, 2011) that using mixed methods enriches the understanding of complex health care issues, particularly the context of health care and its processes.

From a content analysis of 232 social research articles published between 1994 and 2003, Bryman (2012) identified sixteen reported benefits of using mixed research methods. The

content analysis investigated the initial rationales reported for mixing qualitative and quantitative methods and compared these with the final reported benefits of using mixed methods in practice. Over a quarter of studies (n=62, 26.7%) did not report initial reasons for using mixed methods yet all except one (0.4%) reported practical benefits from mixing methods. Most frequently cited was the ability to use data from one method to enhance findings from another, thereby providing more complete accounts of phenomena.

In summary, mixed methods are seen as a natural consequence of pragmatism and are widely used in social and health care research. Although mixed methods might require a wider skill set and more resources than a single approach, there are benefits associated with their use. Consequently mixed methods were used in this project because they fitted with the pragmatic stance of the researcher (a nurse with qualitative and quantitative research experience) and because the research questions were suitable for both qualitative and quantitative investigation.

3.6.1 Integrating mixed methods

For mixed methods research to be robust and useful, not only must each component demonstrate scientific rigour but components should integrate meaningfully with each other (Murphy et al., 2014; Simons and Lathlean, 2010; Creswell and Plano Clark, 2007; Gerrish and Lacey, 2010). O’Cathain, Murphy and Nicholl (2010) argued that integration is vital to achieve a gestalt effect where the overall study outcome exceeds “the sum of its parts” (p1147).

3.6.1.1 Rationale for integration

Sandelowski (1995) defines and criticises the concept of triangulation as the belief that in mixed methods research, findings from one method could be integrated to cross-check the truthfulness of findings from another method. Sandelowski (1995) argues that defining triangulation as a two-dimensional concept of convergent validity fails to account for multiple perspectives and therefore fits poorly with an interpretivist paradigm. Sandelowski (2000) adds that discrepancies between data sources should be seen as opportunities for deeper interpretation and suggested the concept of complementarity, concluding that the three principal aims of integrating mixed methods data are to

triangulate between multiple data sources or data types, to complement or enrich analyses and to develop future data collection or analysis.

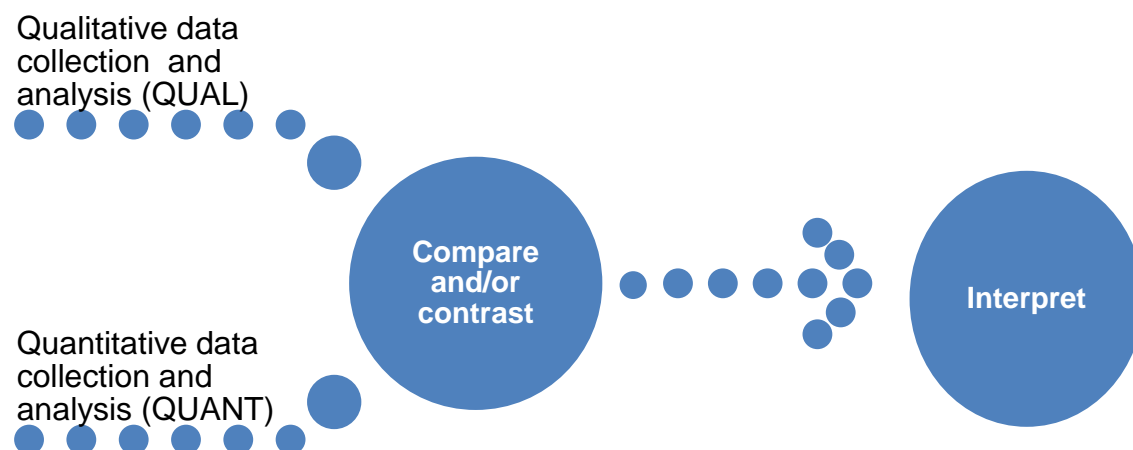
Therefore in this study triangulation between findings from multiple data sources and types was used to enable the type of enhancement suggested by Sandelowski (2000) and reported by Bryman (2012) (see 3.6).

3.6.1.2 Sequencing integration

Researchers should consider the sequencing or timing of integration (Creswell, 2014). Some authors suggest that data should be analysed separately using methods appropriate to the approach, then combined for interpretation (Sandelowski, 2000; Creswell, 2014). Elsewhere it has been suggested that depending on the mixed method approach selected, data be combined earlier i.e. at the analysis stage, (O’Cathain, Murphy and Nicholl, 2010). Nevertheless Creswell and Plano Clark, (2007) suggest a convergent parallel mixed methods design is a straightforward approach favoured by relatively new researchers, where data are combined after analysis. Although Creswell (2014) cautions that convergent approaches may involve intense data collection phases where collecting multiple forms of data simultaneously requires a research team, nevertheless he also argues that such concentrated data collection tends to shorten the overall study duration.

Taking these points into consideration, the researcher adopted Creswell and Plano Clark's (2007) convergent parallel design (see Figure 3-1) because it was straightforward and although data collection would be intense, the study was more likely to be completed within the funded time limit.

Figure 3-1: Convergent parallel mixed methods design, adapted from Creswell and Plano Clark (2007)



3.6.1.3 Weighting methods in integration

It is also relevant to consider how researchers prioritise components of mixed methods studies. Bryman (2012) argued that prioritising may involve drawing artificial distinctions between methods. In convergent parallel mixed methods designs qualitative and quantitative data are typically weighted equally (Creswell, 2014). Nevertheless systematic reviews of 118 mixed methods studies in health services research (O’Cathain, Murphy and Nicholl, 2008) and 80 mixed methods studies in complementary medicine (Bishop and Holmes, 2013) identified that quantitative elements of mixed methods studies were better reported than qualitative components. In this study, although the main investigative effort was qualitative, equal weighting was allotted to qualitative and quantitative data.

3.6.2 Summary of the research approach

In short, the research questions were best answered using both qualitative and quantitative research methods. Using mixed methods was a pragmatic approach to answering the research questions and fitted with the philosophical stance of the researcher. It was anticipated that using mixed methods would yield rich data and increase the study’s ability

to answer the research questions. Data were collected and analysed concurrently then combined for interpretation.

Having justified the research approach, this review now considers the challenges in end-of-life research before addressing the individual study components in more detail.

3.7 Challenges in end-of-life data collection

Rhodes and Nocon (1998) stated that it is best to obtain views on illness and care directly from service users. According to Addington-Hall, Bruera, Higginson and Payne (2007) research in end-of-life care is often difficult. Patients may be too sick to participate, may die before recruitment or during studies or may be unable to give informed consent to participate. Ethical and sensitive approaches are therefore required. Some of these difficulties influenced the choice of data collection methods and are discussed in later sections.

3.8 Using multiple data collection sites

Addington-Hall, Bruera, Higginson and Payne (2007) suggested that multi-centre designs may be necessary to obtain sufficiently large samples in end-of-life studies because of common difficulties in recruiting. Hence multiple study sites were used in this research to maximise the potential sample size. Additionally, using multiple sites helps achieve a varied qualitative sample, may enhance the generalisability of quantitative findings and can enable comparisons between site subgroups (Polit and Beck, 2008). Polit and Beck (2008) recommend fieldwork at the conceptual stage of the research process. For this study, initial fieldwork suggested that four study sites would be sufficient (see 3.9.5.2).

3.9 Quantitative element of the study

The quantitative element of the study had two purposes. It was used to answer the first and third research question on predictors of care pathway use. And secondly, quantitative data

supplemented qualitative accounts of decision-making, processes and care experiences. The quantitative design is now considered.

3.9.1 Quantitative design

A descriptive correlational design was selected to investigate predictors of care pathway use and outcomes. According to Grove, Gray and Burns (2014) the purpose of a correlational study is to investigate relationships, or associations, between two or more variables in a group. Harris and Taylor (2008) stated that the ordering and prediction of inter-variable associations may be explored using inferential statistics. Therefore it was anticipated that variables on end-of-life care could be collected and analysed descriptively, while predictive associations with pathway use could also be explored. However, Bland and Altman (2011) cautioned that causality cannot be inferred from correlations between variables. The researcher remained mindful of this point.

In summary, a descriptive correlational design was used to answer the first and third research questions in this study.

3.9.2 Quantitative data source

Casenotes were a suitable data sources for the quantitative study component. Casenote data have been used to evaluate aspects of end-of-life care in multiple studies in the US and the UK (SUPPORT Principal Investigators, 1995; Pugh, McEvoy and Blenkinsopp, 2010) and in UK clinical audits (Marie Curie Palliative Care Institute Liverpool and Royal College of Physicians, 2011).

3.9.3 Quantitative data in a mixed methods study – a practical example

Casenote review has been used successfully in a mixed methods study, which like the study reported here, sought to investigate a complex intervention. Benning et al. (2011) undertook a mixed methods study across 22 UK hospitals to evaluate the effect of a complex intervention to improve patient safety. They used quantitative casenote review (n=1237) to examine care quality, care processes and mortality. Additionally, while ethnographic observation and qualitative interviews (n=60) were used to examine staff

behaviour and views, Benning et al. (2011) also collected quantitative data on staff attitudes and patient satisfaction via staff (n=25,410) and patient (n=21,834) surveys. Apparently contradictory findings from each study component were compared and contrasted to build a complete picture of the complex intervention and its effects. Benning et al. (2011) concluded that their mix of methods yielded useful and robust data. While sample sizes were much smaller in this study, it was anticipated that as with Benning et al. (2011), using casenote review would generate quantitative data to answer the first and third research questions, and to provide information on experiences and decision-making in relation to question two.

3.9.4 Casenote review tool: justification and components

From the literature review it was clear that clinical and demographic variables such as age, sex, comorbidity, stroke type and stroke severity were associated with mortality in acute stroke. Therefore it was reasonable to evaluate such variables in relation to use or non-use of an end-of-life care pathway and its outcome. Further data were required on decision making, care processes and care experiences. Using a standardised data extraction tool reduces the likelihood of researcher bias in data collection (Gerrish and Lathlean, 2015). Therefore, as in Benning et al. (2011), a data extraction tool was developed for this study. The components are now considered.

First, demographic and clinical data are collected routinely in Scotland for every acute stroke admission by the national Scottish Stroke Care Audit (2015). It was anticipated that some of these data could be used in this study. Second, the Scottish Stroke Care Audit (SSCA) also record Counsell, Dennis, McDowall and Warlow's (2002) Six Simple Variables for both haemorrhagic and ischaemic stroke. The Six Variables model incorporates social, functional and clinical variables, both pre-stroke (age, living alone, independence with Activities of Daily Living) and at first clinical assessment (Glasgow Coma Scale verbal score, ability to raise both arms, ability to walk). The model has been shown to be a valid measure of survival in acute and hyper-acute stroke studies (Reid et al., 2007) and these data were therefore collected for this study.

Additionally, data that were not routinely collected were also required to be extracted from casenotes in this study. As discussed earlier (see 2.9.1), multiple co-morbidities have been linked with higher rates of death within the first 30 days after stroke (Saposnik et al., 2008). Saposnik et al. (2008) measured comorbidity using the index described by Charlson, Pompei, Ales, and MacKenzie (1987) and validated for use in ischaemic stroke cohorts (Goldstein, Samsa, Matchar and Horner, 2004). The index has also been used in studies of intracerebral haemorrhage (Bar and Hemphill, 2011) and according to Johnston et al. (2015) has been widely used in many patient populations. Therefore the third source of data selected for the casenote review tool in this study was the Charlson Comorbidity Index (CCI). The CCI was suitable because it was developed for use in casenote review (Charlson, Pompei, Ales and MacKenzie, 1987) and therefore would suit the planned quantitative data source. Although according to Johnston et al. (2015) extracting CCI data manually from casenotes is time-consuming, this study was likely to involve a small sample (see 3.9.5.2) and therefore CCI data extraction was achievable.

The fourth type of data was not routinely collected and therefore had to be extracted from casenotes. These were quantitative data on use or non-use of an end-of-life care pathway, care variables, resuscitation and feeding decisions.

3.9.5 Casenote review: sampling

3.9.5.1 Justification for prospectively identifying casenotes

Mann (2003) suggests that researchers undertaking observational studies may address difficulties in recruiting prospectively by using retrospective sampling, thereby accessing cohorts which are already clearly identified. In this study, while a retrospective random sample of casenotes may have been achievable, the researcher judged that prospective sampling would enhance integration of the study's mixed methods elements because the quantitative casenote data would be contemporaneous with the qualitative data.

3.9.5.2 Justification of casenote review sample size

Although calculations may be used to generate sample sizes in probability sampling (Sedgwick, 2013), approaches in non-probability studies are less clear-cut. For descriptive quantitative studies, such as that reported here, some authors (Hardon, Hodgkin and Fresle,

2004; Polit and Beck, 2013) agree that larger sample sizes are needed if data are very varied i.e. study groups are heterogeneous. Yet Gerrish and Lacey (2010) and Polit and Beck (2013) caution that large sample sizes cannot compensate for a biased sampling design. Additionally Hardon, Hodgkin and Fresle (2004) advise that where groups are homogeneous, samples can be relatively small, with a minimum of 30 in each group studied.

In quantitative studies it is recommended that researchers seek statisticians' guidance with sample sizes (Hardon, Hodgkin and Fresle, 2004; Gerrish and Lacey, 2010; Polit and Beck, 2013). Further, Hardon, Hodgkin and Fresle (2004) argue that sample size is also driven by practical considerations such as time and funding resources. Hence Polit and Beck (2013) recommend clinical fieldwork as an integral preparatory stage of the research process, so the researcher can establish what sample size is achievable in the study sites to which they have access.

Taking the above points into consideration and in keeping with the researcher's pragmatic stance, it was decided to balance sample size against the practical restrictions of having one data collector and multiple study sites. Clinical fieldwork established patient admissions and deaths per site and hence numbers of casenotes available for review were estimated. Initial fieldwork suggested that four study sites might yield a manageable number (n=100). Statistical advice was sought as to whether the estimated number was sufficient for analysis and the statistician agreed the proposed sampling strategy.

3.9.5.3 Justification for using consecutive sampling

In this study consecutive sampling was used to select casenotes. Polit and Beck (2013) define consecutive sampling as a non-probability (i.e. non-random) sampling method where all individuals from an accessible population are recruited over a set time-period or where the researcher pre-specifies the number of consecutive cases to be recruited.

Gerrish & Lacey (2010) suggest that non-probability sampling may be used if probability sampling is impossible. According to Gerrish & Lacey (2010) probability sampling is the preferred type of sampling in quantitative research because it reduces the risk of bias and maximises generalisability. Nonetheless, probability sampling requires identification of the study population before sampling may be undertaken (Polit and Beck, 2008) and Gerrish &

Lacey (2010) indicate this creates difficulties for many health care researchers seeking to investigate poorly defined populations, as was the case in the study reported here. Further, Gerrish & Lacey (2010) argue that in many health care settings it is preferable to use less rigorous non-probability sampling, and generate some knowledge, than not to undertake studies at all.

Polit and Beck (2008) caution that non-probability sampling may lack representativeness i.e. the researcher may not sample key sections of a target population and thus recruit a biased sample. They argue non-probability sampling is acceptable where researchers sample with caution, draw conclusions carefully and replicate studies. Therefore non-probability sampling was judged suitable for this study and findings were not assumed to be generalisable.

Of the non-probability sampling strategies available, Polit and Beck (2013) argue that consecutive sampling holds a lower risk of bias than convenience or purposive sampling because all cases are enrolled thereby reducing sampling bias. Furthermore, the potential for seasonal bias may be reduced if the data collection period is long enough.

Taking these arguments into consideration, a prospectively identified consecutive sample of casenotes for patients who died or whose care involved the LCP, in multiple Scottish acute stroke units, was used to answer the first and third research questions.

3.9.6 Quantitative data analysis

Duffy and Jacobsen (2005) identify three purposes of statistical analysis: to summarise data in a meaningful way, to identify relationships between variables and to make generalisations to a wider population.

The casenote review was used to generate statistical descriptions such as means and frequencies to supplement qualitative accounts of decision-making and care experiences. According to Trochim (2006) univariate descriptive statistics are used to summarise and describe samples and data in a study, and therefore form the backbone of most quantitative analyses. Trochim (2006) suggests that although using one variable to describe many observations may risk losing detail or even introducing distortion, using univariate analysis enables useful comparisons to be drawn between individuals or groups. It was anticipated

that this mixed methods study would generate rich detail from qualitative data therefore using univariate quantitative analysis was acceptable.

In this study, correlations between casenote variables were explored to answer the second research question on care experiences and decision-making. Further, Harris and Taylor (2008) state that while correlations indicate the strength of inter-variable associations, inferential statistics such as regression analyses may be used to examine the nature of those associations in terms of ordering and prediction. Thus regression analysis was used to examine predictors of the dependent variable of interest i.e. use or non-use of the care pathway. According to Altman (1991) logistic regression analysis can be used for dichotomous outcome variables and therefore logistic regression was judged appropriate in this study.

Peat and Barton (2008) recommend that a formal statistical analysis plan be developed before any analysis is begun. The plan should specify the questions to be answered and the variables and tests to be used.

Taking these points into consideration, statistical support was used in planning this study. The statistical analysis was planned in advance, adopted univariate analysis to yield descriptive data to complement qualitative data and employed logistic regression to examine predictors of care pathway use.

The main qualitative element of the study is now considered in more detail.

3.10 Qualitative element of the study

3.10.1 Qualitative framework

For this study, a modified grounded theory approach was judged suitable. Charmaz (2013) contends that constructivist grounded theory is situated within a pragmatic research paradigm, a view that underlines the method's suitability for this study. Other qualitative approaches were considered but did not appear to fit all the research questions or ethical considerations in this study. For example, phenomenology is useful for exploring individuals' experiences of a single phenomenon (Polit and Beck, 2008) and would therefore have been suitable for investigating the second research sub-question on

experiences of end-of-life care pathway use. However, phenomenology requires in-depth interviews, possibly repeated with the same participants (Moule and Goodman, 2014) which might have been distressing for some proposed participants in this study i.e. bereaved relatives.

Additionally, the other research sub-question concerned decision-making processes, a topic for which phenomenology was not ideally suited. On the other hand, the work of Glaser and Strauss (1966, 1967) showed that a grounded theory approach could be used to investigate end-of-life care processes while also uncovering experiences of staff, patients and families. Despite the view of Glaser and Strauss (1968) that only sociologists could generate sociological theories, Malterud (2001) argues that health care research does not seek to replicate social science but to generate new medical knowledge (see 3.3). This view links with Lingard, Albert and Levinson's (2008) observation that grounded theory studies in health care do not typically generate hypotheses but rather seek to explain processes or social actions within the data (Lingard, Albert and Levinson, 2008).

Bryant and Charmaz (2007) suggest that the practical relevance of grounded theory accounts for the method's ongoing popularity in health services research. Further, according to Moule and Goodman (2014) its focus on human interaction makes grounded theory particularly well-suited to studying many aspects of health care delivery. Therefore a grounded theory approach appeared suitable for qualitative data collection in this study. Differences between classic grounded theory and modified grounded theory are now reviewed.

Classic grounded theory research was developed by Glaser & Strauss (1968), who after their observational studies of care of the dying in 1966 and 1967 (see 2.8.6) published a landmark text reporting their method. Glaser & Strauss (1968) defined grounded theory as theory which arises from data. They argued that their approach i.e. collecting data to develop a hypothesis inductively was the novel opposite of the hypothesis-testing approach then commonly used in sociological research. Their method involved exhaustive coding and comparison of data, iterative data collection, using the evolving theory to guide sampling (theoretical sampling) and extensive use of research memos.

Modifications to the method were later described by Strauss and Corbin (1998) and then by Charmaz (2000), who suggested the modification known as constructed, or constructivist,

grounded theory. Charmaz's grounded theory embraces constructivism, accepting that emerging theory is constructed by researcher and participant, rather than being a found object (Charmaz, 2000). Charmaz's constructivist grounded theory uses the methodology of Glaser & Strauss (1968) but moves away from their paradigm, criticised by Bryant (2003) as positivist. Hence Bryant and Charmaz (2007) report that in the decades following its first use, grounded theory has become a contested concept.

The literature shows debate over what constitutes grounded theory. Bryant and Charmaz (2007) posit that the term 'grounded theory' is used interchangeably by researchers to mean either the set of methods employed or the product of a study i.e. the resultant theory. In fact, the term 'grounded theory' is used variously to refer to a qualitative research tradition (Polit and Beck, 2008), a specific set of methods or their end product (Urquhart, 2013; Bryant and Charmaz, 2007), to a study design (Birks and Mills, 2011) or to a research movement (Berterö, 2012). In this study, grounded theory methods were used with the aim of producing a theoretical understanding of the data. Producing theory is discussed in more detail in 3.10.1.1. First, the essential components of a grounded theory approach are considered.

3.10.1.1 The elements of grounded theory

While the nature of grounded theory is contested, there is general agreement (Charmaz, 2013; Berterö, 2012; Birks and Mills, 2011; Hutchison, Johnston and Breckon, 2010; Lingard, Albert and Levinson, 2008; Bryant and Charmaz, 2007; Charmaz, 2006; Bluff, 2005; Charmaz, 2000; Strauss and Corbin, 1998; Glaser, 1978) that to generate deep understanding of social processes, grounded theory studies should demonstrate some of the following features:

Concurrent data collection and analysis: Distinguishes grounded theory from other types of research where analysis typically happens at end of data collection (Birks and Mills, 2011). Datasets are commonly comprised of field notes from direct observation or interview notes or transcripts (Polit and Beck, 2008).

Coding and categorising data: Researchers identify groups of words expressing similar concepts, attach a summarising coding label and group similarly coded concepts together

(Birks and Mills, 2011) either manually on paper or using computer-based organisational software (Polit and Beck, 2008). Charmaz (2006) suggests specific coding techniques to reduce researcher influence on analysis. Such techniques include using detailed line-by-line coding and focusing on the actions of participants by using gerunds, or active verbs, as coding labels.

Analysis by constant comparison: Data from different sources are intensively compared for similarities and differences (Birks and Mills, 2011). Evolving coding tags and categories are similarly compared and contrasted (Birks and Mills, 2011). Accounts differ (Strauss and Corbin, 1998; Charmaz, 2006; Creswell and Plano Clark, 2007) as to how this may be achieved but essentially, constant comparison helps to establish recurrent topics and their variations throughout the data.

Inductive and abductive analysis: In inductive analysis the researcher allows categories or themes to emerge from the data. There is also agreement that towards the end of analysis the researcher requires to think abductively or laterally (Birks and Mills, 2011; Kelle, 2005) in order to make connections between categories and to build a joined-up theory (Urquhart, 2013; Birks and Mills, 2011; Charmaz, 2006; Strauss and Corbin, 1998)

Hierarchical coding processes: Several authors (Birks and Mills, 2011; Creswell and Plano Clark, 2007; Charmaz, 2006; Strauss and Corbin, 1998) describe more than one phase of coding, typically two or three phases, with increasing levels of abstraction. Hence Charmaz (2006) recommends a process of:

- line-by-line coding where data records, usually transcripts, are read and summarised intensively
- focused coding where codes are rationalised, combined into categories and core categories are identified
- axial coding where links are made between categories.

Identification of a core category: Glaser (1978) and Strauss & Corbin (1998) recommend that researchers identify a central thematic or core category that encompasses and may explain the developing theory. Conversely, according to Breckenridge, Jones, Elliott and

Nicol (2012) constructivist grounded theory does not focus on a core category but seeks to develop a holistic picture of participants' lives.

Theoretical and purposive sampling: Sampling is purposively directed to data sources that will help develop emerging coding categories and theory (Birks and Mills, 2011). Purposive sampling is typically used early in studies and is discussed more fully in 3.10.3.2.

Data saturation: Defined as the point of informational redundancy (Lincoln and Guba, 1985) reached in a qualitative study when data collection begins to yield repetitive findings and does not deepen the researcher's understanding of the phenomenon under investigation (Mason, 2010). Originally used by Glaser and Strauss (1967) in reference to evolving grounded theory studies, Mason (2010) reports that the term has become accepted across the qualitative research field and is commonly used to guide qualitative sample sizes. Guest, Bunce and Johnson (2006) posit that data saturation is a broader concept than that of theoretical saturation used in grounded theory studies.

Theoretical saturation: Searching for negative cases and ensuring a full range of perspectives through a maximum variation sample may aid theoretical saturation (Coyne, 1997). Charmaz (2006) uses this term for the completed investigation of a category such that it is thoroughly developed and no new theoretical properties emerge. Guest, Bunce and Johnson (2006) suggest that theoretical saturation occurs when all aspects of the emerging theory have been exhaustively explored through examining variations in the data.

Theoretical sensitivity: Refers to the researcher's awareness of the theory emerging from their data. Glaser (1978) argues that objective sociological principles or laws recognisable to researchers are likely to emerge from the data in a grounded theory study, while other authors acknowledge that the researcher's discipline-specific theoretical background will influence the developing theory (Birks and Mills, 2011). For instance, both Kelle (2005) and Charmaz (2006) recommend that researchers carefully blend theoretical concepts emerging from the data with established theoretical concepts such as agency or biography (Charmaz, 2006) that already form part of the researcher's perspective. Nevertheless both Glaser (1978) and Bluff (2005) warn against the *a priori* use of theoretical codes too early in a study because they might not be a true fit.

Writing memos: Memos are written records of the researcher's thinking during a study. Memos help to trace the development of analysis and coding (Birks and Mills, 2011) and maintain reflexivity, or openness about the researcher's perspective and role in data collection and analysis (Charmaz, 2013, 2006). Clarke (2005) identifies memos as useful data sources and highlights their value in writing up findings.

Producing theory: Glaser and Strauss (1968) stated that grounded theory studies yield both substantive theory relating to actions and processes in the study, and formal theory i.e. higher level generalisable theory. Yet there is some acceptance that the products of a constructivist study will differ from those of classic grounded theory studies. For example Berterö (2012) states that an absolute and generalisable theory may not be produced but rather groups of data categories would be developed that enable the understanding of social interactions and perspectives within a participant group. Charmaz (2013) asserts that constructivist grounded theory aims not for generalisable social theory but rather for a contextualised understanding of a specific research situation, from which elements may be transferable.

In this study, many of these features of grounded theory were used and are reported in the following chapters. These methods were consistent with a Charmazian approach and were used to produce a theoretical understanding of the data.

3.10.1.2 Summary

The constructivist version of grounded theory fitted with the second research question on family and health-care workers perceptions of an end-of-life care pathway. Additionally, Charmaz's (2013) assertion that constructivist grounded theory is situated within a pragmatic research paradigm was consistent with the researcher's philosophical stance. Taking these arguments into account, a Charmazian constructivist grounded theory approach was selected for the qualitative component of the study.

3.10.2 Qualitative data collection

3.10.2.1 Using interviews for qualitative data collection

Qualitative data were used to answer the second research question on perceptions and experiences of pathway use and related decision-making. Silverman (2013) contends that the best data arises without the influence of a researcher and suggests the ‘Dead Researcher’ test for determining the primacy of data: would the data still exist if the researcher were never born, or killed en route to university that day? He argues that there are many sources of such “naturally occurring” (p129) data e.g. observation, public records or organisational records. In this study, observing end-of-life decision-making comprehensively would have required observation not only of staff interactions with each other and with patients, but also conversations between staff and families. However, Payne, Burton, Addington-Hall and Jones (2010) report that such conversations can be complex or distressing. Thus the researcher took the view that it would be unethical and intrusive to seek to observe or record interactions between families and clinicians when patients were known to be dying. Further, qualitative data needed to allow exploration of perceptions and experiences of care, as well as decision making.

Interviewing is suggested by Bryman (2008) as a reasonable alternative for researchers unable to use observation as a data collection method. Bryman (2012) acknowledges that in hard-to-reach research populations, the ideal form of data collection may not be possible and a more practical approach may be required. In this study the decision to use interviews for qualitative data collection was a pragmatic response to issues of ethics and sensitivity. Interviewing is now considered in more detail.

3.10.2.2 Advantages of interviewing

Taylor (2005) identifies that interviewing is useful for exploring attitudes and individuals’ perceptions of their lives, behaviours and environments. Hence the method is useful for answering *how* and *why* research questions. Interviewing also enables researchers to capture participant’s own words and focus on the participant’s priorities. Probing and clarification is possible as is the observation of non-verbal behaviour. Interviewing is a flexible way of generating data, requiring only simple equipment such as a voice recorder (Taylor, 2005). Taylor (2005) suggests that although good interviewing is an acquired

skill, researchers can interview successfully using their existing conversation and communication abilities. Hoffmann (2007) suggests that successful interviewers need multiple skills simultaneously, to follow content and the direction of discussion, direct where needed, anticipate, observe the participant, handle difficult behaviour like aggression, anger, tears and to remain reflexive during the interview. The researcher in this study had qualitative interviewing skills acquired during previous work (Cowey, Smith, Booth and Weir, 2012).

3.10.2.3 Disadvantages of interviewing

Atkinson and Silverman (1997) contest the idea that interviews faithfully reflect biographical experience, arguing that interview data is self-report data and does not necessarily reflect actual or future behaviour. They caution further that because interviews are social constructions, interview data do not necessarily reveal the innermost perspectives of participants. Conversely, in a later publication Silverman (2013) reports a pragmatic counterargument offered by Clive Seale. Seale agrees that interviews yield self-report data but argues that such data are particularly useful in relatively unexplored areas where researchers need to gather initial evidence.

Taking these arguments into consideration, interviewing remained a suitable method for data collection, providing the apparent limitations of interview data were accepted. The study reported here was conducted from a pragmatic stance that was comfortable with the concept of social construction. Further, interview data would be considered with other data i.e. quantitative data from casenotes. It was anticipated that this approach would situate and enhance constructed accounts from interviewees. Thus using interviews for data collection fitted with the researcher's pragmatic philosophical stance and with a mixed methods approach.

3.10.2.4 Defining interviewing

Interviews are structured discussions that elicit insight (Barlow, 2014). Deakin and Wakefield (2014) report that interviewing is the most commonly used data collection method in social research. Although Holloway and Wheeler (2010) accept that

interviewing may appear a natural research choice for clinicians accustomed to asking patients questions in everyday practice, they caution that interviews are more than ordinary social interactions, being subject to additional defined rules or processes. For example, it has been argued that interviews are always structured to some degree (Mason, 2002; Taylor, 2005). Barlow (2014) describes a structural continuum from unstructured to highly structured interviews. Bryman (2008) aligns structured interviewing with quantitative research while several authors agree that semi-structured and unstructured interviews belong within a qualitative research paradigm (Edwards and Holland, 2013; Bryman, 2008; Taylor, 2005). Unstructured interviews are time-consuming and hence expensive both to conduct and analyse (Gerrish and Lathlean, 2015). Therefore semi-structured interviewing was selected for this study.

Interviews may involve single or multiple participants and may be conducted face-to-face, by telephone or using webcams (Bolderston, 2012). They may be repeated longitudinally with the same participants to deepen the researcher's insights (Holloway and Wheeler, 2010; Charmaz, 2001). Alternatively in studies using a grounded theory approach, such as the study reported here, interviews tend to be stand-alone i.e. not repeated (Wimpenny and Gass, 2000).

Mason (2002) states that semi-structured interviewing involves:

- an interaction and spoken exchange between researcher and participant(s)
- relaxed conversational style
- a set of points for discussion
- a flexible approach to the sequence of discussion that also allows the exploration of unexpected topics
- an assumption that data are generated jointly by participant and researcher, rather than collected objectively.

Hoffmann (2007) agrees with Mason, describing a shift from older concepts of interviewing where participants were seen as passive receptacles of information which researchers must extract without contaminating. Instead Hoffman argues it is increasingly

accepted that in qualitative interviewing participants and interviewers generate data together. The challenge for interviewers is to conduct the interview so that data generated are as near to the participant's viewpoint as possible.

Semi-structured interviewing was therefore selected for this study because it fitted with the researcher's pragmatic approach to research. Further, as Barlow (2014) argues, interviewing allowed the researcher to explore similar issues with each participant and hence compare participants' views. Finally, Barlow (2014) suggests the method is useful when the researcher has some prior knowledge of the topic, as was the case in this study, but seeks a deeper understanding of key issues.

3.10.2.5 The interview guide

The key aspect of interviewing is listening. Interviewers should listen actively, encouraging responses without dominating (Bryman, 2008). Although some interviewers avoid using tools to guide interviews in case the natural flow of conversation is inhibited (Charmaz, 2001), many researchers use tools such as interview topic guides to facilitate the interview and maximise the potential to answer the research question (Edwards and Holland, 2013).

The interview guide may be a brief list of prompts or a list of fully developed questions (Bryman, 2008). The researcher's prior knowledge or existing literature may be used to construct an initial topic guide that can be piloted and then modified as the study progresses (Bryman, 2008). The interview guide typically contains questions that need to be addressed in order to answer the research questions (Edwards and Holland, 2013). However, the interview schedule does not simply restate the research questions. Instead, the research questions may be split, simplified and re-worded to ensure they follow a natural conversational flow and are understandable to participants (Edwards and Holland, 2013).

Kvale (1996) identifies nine types of questions typically used in interview guides. These include opening, follow up, probe and indirect questions. Kvale (1996) recommends that researchers tailor the question type according to the interview stage. Charmaz (2001) agrees that the question-type should be selected to suit the beginning, middle and end

stages of the interview but suggests a simplified range of three main question types. Initial questions should be open requests for information, intermediate questions should focus on what has already emerged, and the end of interview, Charmaz (2001) suggests, is suited to more reflective questions.

Charmaz (2001) recommends avoidance of closed questions, arguing they impose too much of the researcher's view on the conversation. Taylor (2005) agrees, stating that researchers should avoid leading questions, confusing multiple or double-barrelled questions, and avoid being too directive by sticking rigidly to the topic guide. Whatever the question type, the schedule must allow flexibility in the flow of the interview (Bryman, 2008). Further, Bryman (2008) argues that the researcher does not know the participant's world and so must not close down exploration by using a fixed line of questioning. Instead the investigative approach should allow unexpected data to emerge (Bryman, 2008). Taylor (2005) recommends that the schedule be modified in the light of preceding interviews - or in grounded theory studies, in the light of emerging theory - and that researchers ensure participants' views are captured accurately by clarifying meanings with them.

Taking these points into consideration, a flexible interview guide (see 5.10.1) incorporating a range of question types was developed from the research questions and the literature reviewed in Chapter One.

3.10.2.6 Practical considerations in interviewing

Bryman (2008) argues it is important that researchers' are familiar with participants' worlds or work setting, because familiarity helps researchers understand the context and content of participants' reports. Hoffmann (2007) describes how in her study, her familiarity with the coal mine where a participant worked helped to establish trust between her and participant and elicit rich deep information. In the study reported here, the researcher was a registered nurse with a clinical and research background in NHS acute hospital care. Therefore she was partly familiar with the context of participants' care experiences.

Interviews should be recorded, and audio recording is preferable to note-taking because it allows the interviewer to focus on the conversation (Bryman, 2008). Normally electronic audio recording would be used but if participants refuse or equipment fails Bryman (2008) recommends proceeding with the interview and taking detailed notes. Recording interviews allows researchers to scrutinise the language used and the sequencing of interactions. Having an accurate record of the interview not only counteracts recall bias on part of researcher, but also enables repeated analysis, by other researchers (Bryman, 2008). Interview settings need to be quiet and private so that participants feel free to speak, and to maximise sound recording quality (Barlow, 2014; Bryman, 2008). Field notes should be made afterwards, noting details of the interview e.g. if the participant seemed distressed or angry, if there were any interruptions, if others were present and if any unexpected ideas emerged (Bryman, 2008). Hence in this study, interviews were digitally recorded and field notes made.

3.10.2.7 Transcribing interview recordings

Interview voice recordings are commonly transcribed in order to generate text data that researchers can manipulate during analysis (Bird, 2005). Transcribing is time consuming. Bryman (2008) estimates that one hour of voice recording might require five or six hours to transcribe.

Kvale (1996) argues that transcribing spoken data is not a like-for-like transfer. Rather, because the transcriptionist imposes punctuation and sequencing, transcriptions are themselves constructions of interviews. Bird (2005) further argues that where researchers undertake their own transcribing, transcription becomes analysis because comparisons are drawn spontaneously with previous interviews and transcripts. Hence Bird (2005) and Bazeley (2007) agree that researchers profit from undertaking their own transcription. This was a benefit in the study reported here as there was no funding for transcription hence the researcher was also the transcriber.

On a separate point, Bazeley and Jackson (2013) emphasise the difference between transcriptions and raw interview data. They suggested that transcript text can seem lifeless because the text does not capture the context and the non-verbal communication seen

during the interview. Bazeley and Jackson (2013) therefore recommend that researchers annotate transcript text to indicate events within the interview for the benefit of the reading audience.

Nevertheless verbatim transcription is not always necessary (Bryman, 2008) as some interview conversation may be irrelevant to the research. Bazeley and Jackson (2013) support this view, suggesting that verbatim transcription is required where phenomenological, psychological or conversational analysis research is being undertaken. They argued verbatim transcription is less vital where fine nuances of participants' meaning are not required. However, Bryman (2008) cautions that relevance may emerge later in the study and full transcription will be required. Therefore interviews were transcribed verbatim in this study.

3.10.2.8 Attributes for an interviewer

According to Kvale (1996), interviewers must perform multiple activities simultaneously. They should be familiar with the interview guide, must use structure within interviews, starting with purpose, marking the finish clearly, and ask if the participant has questions. Interview questions should be clear and simple and asked in a gentle manner that allows pauses, giving participants time to think. Researchers should be sensitive to participants' speech and behaviour, responding flexibly to participants while also being able to steering and direct the interview. Researchers should challenge or follow up inconsistencies, while being able to remember and relate back to statements made earlier in the interview. Kvale (1996) also suggests that interviewers must be able to interpret, clarify and summarise participants' statements impartially.

Managing the ending of an interview is a key skill. Kvale (1996) recommends that interviewers signal the start and end of interviews clearly to participants. Charmaz (2001) and Edwards & Holland (2013) agree that endings are important particularly if distressing or sensitive topics were discussed. In those cases the researcher must bring the dialogue back to a normal conversational pitch before concluding. Interviews should not end with participants in distress (Charmaz, 2001).

Taylor (2005) proposes that good interviewers should remain self-critical, considering if, for example, they allow enough silence, use probe questions and how far participants direct interviews. To the attributes listed by Kvale (1996), Bryman (2008) adds that interviewers must be able to strike a balance between talking too much and drowning out participants, or talking too little and appearing uninterested. Further, researchers must act ethically, ensuring participants understand the research and how their contribution will be handled confidentially. These points were incorporated into the study ethics application and to the conduct of interviews.

3.10.2.9 Power balance within interviews

According to Taylor (2005) there needs to be a relationship of trust and shared respect between interviewer and participant. Yet Barlow (2014) makes clear that interviews should not become therapeutic exchanges and researchers should not offer advice. Taylor (2005) also argues that the balance of power should be shared in the interview, where the participant can take control and direction. Edwards & Holland (2013) contend that although researchers make the first moves to initiate interviews, participants often negotiate venues and timings; hence power may shift back and forth between researchers and participants during the interview setup process.

Interviewers should also consider their own influence on the interview in terms of their class, gender, position or job (Taylor, 2005). Richards & Emslie (2000) compared two qualitative studies (each n=60), one conducted by a GP and one by a sociologist, both young, white and female and working from the same public health department. They reported that participants responded differently, according to the perceived social status of the interviewers. In the GP study all participants knew the status of the interviewer. Working class respondents were apologetic when criticising doctors and generally deferential, whereas middle class participants responded as equals and assumed that values were shared or assumed shared inside knowledge. Participants from all social backgrounds asked clinical questions and shared personal health problems. In contrast, the sociologist introduced herself to participants as a researcher but did not disclose that she had a PhD. In her interviews, participants asked personal questions about her background, criticised doctors freely and questioned what would happen to their data.

Richards & Emslie (2000) concluded that participants' perceptions of the researcher's professional background could alter the power balance of interviews and the data generated. Researchers, they argue, must consider power balance in interviews and the professional background of data collectors when analysing data. In the study reported here, participants knew the professional background of the researcher. This was considered when interpreting data, particularly from interviews with two relatives who criticised aspects of care and discussed with the researcher that they were also nurses (see 5.22).

Hoffmann (2007) suggests that during interviews the power balance fluctuates between researchers and participants. Hoffman describes how the power balance shifted when a participant became distressed during her interview. The participant needed the researcher to show understanding and compassion, hence power shifted to the researcher. Recognising that the participant's wellbeing was paramount, Hoffman offered to terminate the interview, shifting power to the participant. The participant chose to continue, handing power back to the researcher to continue questions.

The concept of power balance was relevant to interviews in this study because given the sensitive topic, some participants became distressed. Therefore the researcher offered participants control over the interview process, reminding them at the outset that they could choose to stop at any point. Additionally, when participants showed distress the researcher acknowledged their distress and offered comfort or support.

3.10.3 Qualitative sampling

To answer the research questions in this study the qualitative sample should ideally include healthcare professional and patients. However, by virtue of requiring an end-of-life care pathway, it was assumed patients would be too ill to take part. Yet as Addington-Hall and McPherson (2001) point out, researchers have a duty to ensure their samples reflect the population being studied. Therefore, since it was not possible to include patients it was decided to seek proxy data from relatives. It has been argued that using proxies ensures representation of all patients, including those too sick to speak for themselves (Cartwright and Seale, 1990; Addington-Hall and McCarthy, 1995; Lynn et al., 1997). Otherwise, according to Addington-Hall and McPherson (2001) patients in the terminal phase would be under-represented in end of life research.

For reasons of sensitivity, information is often collected some time after bereavement rather than during the terminal illness. The retrospective use of proxy data on end-of life care quality is common in the UK (Addington-Hall and McPherson, 2001; Department of Health, 2012). Additionally Lynn et al. (1997) argues that reports from families are important not only for obtaining patient care data but because the views of relatives also have intrinsic worth. Further, there was some evidence from literature (see 2.10.2) that relatives were involved in end-of-life decision-making and therefore their reports might yield useful data.

3.10.3.1 Retrospective proxy accounts – historical evolution and validity

Some authors have reported problems with the validity of retrospective family reports. Although work from the 1980s (Cartwright and Seale, 1990) suggests poor agreement between proxy and patient reports, this was based upon non-concurrent data. More recently a systematic review (McPherson and Addington-Hall, 2003) of 23 studies showed that proxy data collected concurrently from dying patients and their families demonstrates good agreement on topics such as service provision and activities of daily living but poorer agreement for subjective symptoms like pain and anxiety.

Following their 2003 review, McPherson and Addington-Hall (2004) explored retrospective symptom-reporting further. In their small (n=13) mixed methods study using semi-structured interviews and a symptom rating scale they examined the influence of memory recall bias on proxy retrospective ratings during the bereavement period. At two time points i.e. three to five months and seven to nine months post bereavement, proxies were asked to rate symptoms experienced by their relative in their final illness. Ratings for anxiety remained consistent, while pain and depression ratings tended to diminish between the first and second time points. Hence there was some limited evidence that accurate recall might diminish by seven to nine months post bereavement and this finding was used in timing interview data collection for this study.

In summary, researchers have few options in achieving representative samples of dying patients. Retrospective data from proxies has validity in assessing objective symptoms and service provision, but it is a less valid measure of patients' subjective symptoms.

Notwithstanding, the voice of the family is itself important. These facts strengthened the case for using retrospective proxy reports to gather data for this study. Further, this mixed methods study would include casenote data on symptom management that would allow overall comparison with proxy reports, counterbalancing the known validity issue. In light of McPherson and Addington-Hall's (2004) work on recall bias, it was planned that data collection should take place by six months post-bereavement.

3.10.3.2 Qualitative sample: composition

According to Lincoln and Guba (1985) samples in qualitative studies are not recruited to represent a wider population but to afford understanding of a phenomenon or experience. Therefore samples are chosen purposefully to maximise the researcher's understanding i.e. researchers select participants whose specific attributes or experiences are likely to yield data to answer the research question. Sandelowski (1995) argued that maximum variation sampling was the most commonly used type of purposive sampling. Coyne (1997) identifies that in maximum variation sampling, participants may be varied by demographic characteristics such as age, sex, and occupation or according to political or ideological beliefs. Thus "information-rich" (Coyne, 1997:p629) participants are recruited who vary demographically and experientially. In this way, a range of views and experiences of the phenomenon under investigation can be obtained (Ziebland and McPherson, 2006). Therefore in this study, healthcare professionals of varying seniority, disciplines and clinical experience and bereaved relatives of assorted ages, and relationships with stroke patients i.e. spouses, partners, siblings, parents, children etc. were sought purposively to answer the second research question on clinical decision-making, experiences and perceptions of care.

3.10.3.3 Qualitative sample size

Sample sizes in qualitative research may be driven by several factors. Charmaz (2006) suggests that complex qualitative research questions might require larger samples to ensure issues are thoroughly explored. Additionally, Ritchie et al. (2013a) posit that highly varied research populations of interest as well as budget or resource considerations affects sample

size in a qualitative study. According to Pope, Ziebland and Mays (2000) sample sizes in qualitative studies tend to be small and driven, not by statistical generalisability, but by the ability of the sampled data to answer the research question fully. Many authors link the ability to answer the research question to the concept of data saturation (see 3.10.1.1 for a definition of data saturation).

Nevertheless, data saturation is a contested concept and there is debate over how many interviews might be required to reach the point of data saturation. Morse (1995) suggests 30-50 for grounded theory studies while Creswell (2007) suggests 20-30. Further, Guest, Bunce and Johnson (2006) identify recommendations in the literature ranging from 12 to 35 participants but conclude the recommendations are not based on practice. Hence they argue that data saturation is easier to define than to operationalise. From their review of 60 coded interviews in a multinational African study Guest, Bunce and Johnson (2006) suggest that 12 interviews might be sufficient to achieve data saturation in interview studies using a grounded theory approach. Yet they caution that 12 interviews would probably be insufficient in studies where the research question is broad, the sample is very varied or the data quality is low. Guest, Bunce and Johnson (2006) also warn that data saturation is linked to the researcher's abilities, drive and insight. Further, they argue that highly detailed analysis takes longer to reach saturation, whereas superficial analysis will reach data saturation more quickly.

Mason (2010) examined the size of qualitative samples in 560 qualitative PhD theses published in the UK and Ireland and reported the mean size was 31. A significantly ($p=0.00025$) non-random fluctuation was noted in sample size, with 114 studies (20%) having samples in multiples of 10. From this Mason inferred that pre-meditated sample sizes were used but was unable to conclude whether those sample sizes were inappropriate. Further, Mason (2010) notes the sample sizes tended to be larger than recommended in the literature and suggested possible explanations. Either the PhD researchers did not understand data saturation, or they erred on the side of caution or they were pressured by the expectations of external bodies such as ethics committees or funders. Last, Mason also suggests that inexperienced researchers may require larger samples to achieve the richness of data that more experienced researchers would accrue in smaller samples.

In a methods review paper Baker and Edwards (2012) asked 14 'expert' qualitative researchers (e.g. Bryman, Denzin, Charmaz, Flick) and five early career researchers how many interviews were required in a qualitative study. Suggested sample sizes ranged from one to 50, with one respondent indicating 25 interviews for a Masters project and 50 for a PhD. In addition to data saturation the respondents indicated that the answer depended on epistemological approach, methodology and practical considerations such as resources (time, funding), ease of accessing participants or the expectations of examiners or ethics committees.

On a practical level, Francis et al. (2010) suggest four principles for achieving and reporting data saturation:

- Stating the initial intended sample size at the study outset. This should be linked to the heterogeneity of the sample and scope of the research question, with highly varied participants or complex questions requiring larger initial analysis samples.
- Stating in advance i.e. at study outset how many interviews will be allowed to yield no fresh ideas before it is decided that data saturation is reached ("stopping criterion" p8).
- Using a minimum of two independent coders
- Reporting data saturation handling in any published papers.

Taking these issues into consideration, in this study purposive sampling was used to recruit a group of healthcare professionals and relatives bereaved by stroke. The researcher aimed for maximum demographic variation among participants. It was anticipated that sampling would continue until data saturation was reached. Data saturation would be judged using a stopping criterion (Francis et al., 2010) of three interviews. It was recognised that the relative inexperience of the researcher with grounded theory might increase the required sample size, as would the diversity of participants and the broad scope of the research questions. Flexibility in determining sample size was written into the study protocol. The other principles recommended by Francis et al. (2010) were also adopted and are reported in Chapter Five.

To complete this section on qualitative interviewing, the use of a survey tool in conjunction with interviews is now considered.

3.10.4 Questionnaire use in interviews

In this mixed methods study a questionnaire (VOICES II) was administered at the end of each interview with bereaved relatives. The questionnaire is shown in Appendix 2 and is discussed in the following section. The Views of Informal Carers – Evaluation of Services (VOICES) II questionnaire was used to collect descriptive quantitative data, complementing qualitative accounts of decision-making processes and care experiences and providing context for the qualitative data.

The original short form VOICES tool was developed using the interview schedule from Addington-Hall and McCarthy's (1995) Regional Study of Care for the Dying in England. The Regional Study schedule was shortened in collaboration with stakeholders i.e. healthcare professionals in hospital and primary care and care purchasers and the resulting VOICES tool was piloted with bereaved relatives and reviewed by stakeholders (Addington-Hall et al., 1998). It contained 158 items on care needs, service provision and care satisfaction. The VOICES tool was validated for face-to-face or postal administration by using an RCT to compare responses from its administration in 69 interviews and a postal sample of 161 respondents (Addington-Hall et al., 1998).

Response rates were similar in both groups. Not surprisingly there were more missing data in the postal group, but responses were similar for 147 out of 158 items, although interview participants were more likely to give higher ratings of satisfaction and symptom control. The researchers attributed some of the response differences between groups to the fact that in interviews the researchers could clarify terms for participants. Therefore Addington-Hall et al. (1998) suggested that the tool was acceptable for postal surveys of care, as well as face-to-face interviews.

The VOICES tool was thereafter modified into a core version with disease-specific versions for measuring end-of-life care quality in stroke, heart failure and community care (Hunt, Shlomo, Richardson and Addington-Hall, 2011). The stroke-specific version (VOICES II) was devised following literature review and consultation with healthcare professionals (n=21) and bereaved relatives (n=6) (Young, Rogers and Addington-Hall,

2008). The new VOICES II tool contained nine sections: help at home, care from GPs, nursing/residential home care, last hospital admission, symptoms and treatment, care in the last three days of life, circumstances surrounding death, demographic information and views on completing the questionnaire. Although further validation or piloting was not reported by Young, Rogers and Addington-Hall (2008), the VOICES II tool was adopted by the UK Department of Health as a valid measure of carer satisfaction with end-of-life care services (Department of Health, 2012).

It is recommended that the VOICES II tool be treated as a question bank rather than a questionnaire with fixed content (Addington-Hall, 2006). Therefore in this study the stroke-specific sections relating to the last hospital admission, care in the last three days of life and to circumstances surrounding death were used. In total these sections contained 28 fixed response questions, with free text response options for nine of the questions.

To summarise, the VOICES II items were judged suitable for use in this study for several reasons. First, the items addressed proxies' evaluations of services and patterns of service use, found to show reasonable agreement with patient self-reports (Addington-Hall and McPherson, 2001). Second, the tool was tailored to evaluate end-of-life stroke care and therefore fitted with the research aims. Third, it had been used to evaluate end-of-life stroke care in the UK (Young et al., 2009; Young, Rogers and Addington-Hall, 2008) and so it was anticipated that comparisons might be drawn between findings in this study and previously published data. Finally it was anticipated that by using only three sections from the tool, descriptive statistical analysis for the quantitative variables and thematic qualitative analysis for free-text sections would be achievable within the study time limits.

Measures to ensure rigour in the study are now addressed, first in relation to the quantitative component, thereafter the qualitative element.

3.11 Ensuring rigour in the study

In quantitative studies, the term 'methodological rigour' refers to the internal and external validity and reliability of the study (Polit and Beck, 2013). Different terms, arising from the work of Lincoln and Guba (1985) are used for these concepts in the qualitative paradigm. Lincoln and Guba (1985) proposed an overarching concept of 'trustworthiness'

to ensure objectivity in naturalistic, or qualitative, inquiry (see Table 3-1). The concept has four domains:

Table 3-1 Terms for a naturalist epistemology of trustworthiness, as proposed by Lincoln and Guba (1985)

Conventional term	Proposed new term	Proposed operational techniques (Graneheim and Lundman, 2004; Thomas, 2006; Maxwell, 2008; Hannes, 2011; Adams, Bailey, Anderson and Docherty, 2011)
Internal validity	Credibility	Prolonged engagement, persistent observation, negative case analysis, verbatim quotes, maximally varied sample, triangulation, peer review, member checking
External validity	Transferability	Thick description
Reliability	Dependability	Audit trail, peer review, evidence of reflexivity
Objectivity	Confirmability	Audit trail, evidence of reflexivity

Although Lincoln and Guba (1985) have since been criticised for allowing positivism to define their work (Angen, 2000), their terms and operational suggestions are still widely used in qualitative research (Holloway and Wheeler, 2010). Issues of rigour are now discussed with reference to this study. First, issues of rigour in the quantitative element are addressed. Thereafter Lincoln and Guba's four domains are considered in relation to the qualitative study component.

3.11.1 Rigour in the quantitative study component

According to Polit and Beck (2013) the principal considerations of rigour in quantitative studies are internal and external validity, reliability and objectivity (see Table 3-1). There were two quantitative elements in this mixed methods study: the casenote review and the VOICES II questionnaire. Issues of rigour in these are now considered.

3.11.1.1 Rigour and the casenote review

Steps to minimise bias i.e. use of a standardised data extraction tool and consecutive sampling in the casenote review are addressed in 3.9.4 and 3.9.5. Additional measures to enhance internal validity and objectivity included using valid and reliable measures such as the Charlson Comorbidity Index and the Six Simple Variables items (see 3.9.4). The likelihood of sampling bias was further reduced by ensuring casenotes were identified by a

third party i.e. the clinical team, not the researcher. Although the small sample size and the use of non-probability sampling limited the external validity of the casenote review (see 3.9.5.3), it was reasonable to believe that the sample would be representative of many adult patients dying after acute stroke in Scotland.

3.11.1.2 Rigour and the VOICES II questionnaire

The validity and reliability of the VOICES II questionnaire are addressed in 3.10.4. Using a pre-designed, standardised tool heightened objectivity because there was less scope for the researcher to vary the questions. Reliability was enhanced because the questionnaire was administered face-to-face by one researcher. Nevertheless it was anticipated that the sample would be small hence generalisability would be unlikely.

3.11.2 Rigour in the qualitative study component

3.11.2.1 Credibility

According to Holloway and Wheeler (2010) a study is credible in so far as it accurately represents the social realities of participants. Thus researchers must demonstrate that they have spent long enough in the field to capture participants' viewpoints comprehensively (Hannes, 2011) and explored negative cases i.e. participants who report experiences that differ from the majority (Ziebland and McPherson, 2006). Further, Hannes (2011) suggests that researchers report verbatim quotes from participants to show their analysis fits the view of participants, thereby strengthening credibility. Graneheim and Lundman (2004) argue that using a maximally varied sample increases the likelihood of capturing multiple perspectives, thereby answering the research question fully. As discussed in 3.6.1, triangulating between data sources deepens the researcher's understanding by comparing participants' views (O'Cathain, Murphy and Nicholl, 2010; Bryman, 2012) and maximises credibility.

Therefore the researcher in this study aimed to generate a credible volume and quality of data. This was also demonstrated by the length of time spent with a demographically varied group of participants. Negative case analysis and verbatim quotes were used in analysing and reporting the study. The researcher triangulated between data sources i.e.

qualitative interviews, questionnaire responses and casenote review data to increase the credibility of findings.

Holloway and Wheeler (2010) report that some of the techniques designed to enhance trustworthiness in qualitative research are contested. For example, the use of independent coders or peer review of coding has been debated, with Sandelowski (1998) arguing that external analysts lack immersion in the data and thus are poorly placed to peer review emerging themes. Nevertheless Graneheim and Lundman (2004) support the concept of peer review and validation of data interpretations among researchers and participants, arguing that dialogue among researchers aids analysis. This view is endorsed by Ziebland and McPherson (2006) who suggest that discussing data with other researchers can deepen insight and understanding. Therefore this study adopted peer review of coding and analysis.

Another relevant example was that of member checking, or respondent validation. Although member checking is cited as a measure to boost the credibility of a study, its definition is varied. Thomas (2006) identifies several ways in which reviewing analysis with participants i.e. member checking, may be achieved. These included summarising and clarifying issues at interview, asking participants to comment on transcripts, holding informal discussions at study sites, making reports or oral presentations (either preliminary or final) of emerging analysis to stakeholder groups. Stakeholders may be participants, service providers or funders.

Yet some authors sound a note of caution. Sandelowski (1998) argues that modern voice recording reduces the need for participants to check transcripts for accuracy. Further Sandelowski questions how researchers should handle data altered or discarded by participants during member checking. Similarly, Barbour (2001) contends that member checking may sometimes be inappropriate, for example if checking transcripts causes distress or is time-consuming for participants. In such circumstances Barbour argues that member checking may become exploitative. Yet Sandelowski (1998) states that participants can be helpful in giving feedback on analysis, thereby enhancing credibility. More recently Ziebland and McPherson (2006) suggest it is reasonable for researchers to seek views on their analysis from a group of stakeholders unrelated but similar to participants.

Taking these points into consideration, care was required in this study to ensure that member checking did not cause distress to bereaved participants or make unreasonable time demands on healthcare professionals who participated in interviews. Therefore member checking as defined by Thomas (2006) was used to summarise viewpoints or clarify inconsistencies during interviews, and transcripts were not returned to participants for checking. A stakeholder group was used to give views on the emerging analysis.

3.11.2.2 Transferability

Transferability is the extent to which qualitative study findings may be applied to other settings (Holloway and Wheeler, 2010). Because qualitative research uses small non-representative samples findings are unlikely to be directly generalisable, yet certain findings or emergent theory may be transferrable to practice in other settings. Transferability must be decided by the reader or consumer of the research (Hannes, 2011). Consumers can judge transferability if enough description is provided of the original sample, setting, researcher and participant characteristics, and methods (Adams et al., 2011; Hannes, 2011). Such ‘thick description’ (Ryle, 2009; Geertz, 1973) helps the reader decide if the findings might be applied to their own setting. Therefore in this study the researcher collected and reported background data on study sites and participant demographics, while reporting analytical methods clearly.

3.11.2.3 Dependability

A qualitative study is dependable if data have been handled consistently throughout (Graneheim and Lundman, 2004) and have been logically and accurately analysed (Holloway and Wheeler, 2010). Graneheim and Lundman (2004) acknowledge that although the analytical focus may narrow throughout a study, methods for data comparison should remain consistent. Several authors (Graneheim and Lundman, 2004; Adams et al., 2011; Hannes, 2011) agree that dependability is also enhanced by dialogue with other researchers and peer review of coding, and dependability may be demonstrated by a clear audit trail of methods and decisions. Hence in this study peer review of coding was used and an audit trail of analytical methods maintained.

3.11.2.4 Confirmability

Confirmability is the degree to which the researcher leaves aside their own preconceptions and derives findings purely from the perspective of participants (Holloway and Wheeler, 2010).

Some have debated whether qualitative researchers may achieve neutral objectivity. For example Lincoln and Guba (1985) argue that qualitative inquiry is value-based and influenced by the norms and assumptions of the researcher. Reason (1988) argues that researchers' inherent biases should be articulated and included in the analytical process. Several authors (Kuper, Lingard and Levinson, 2008; Maxwell, 2008; Holloway and Wheeler, 2010; Bryman, 2012) agree that although qualitative researchers are unlikely to achieve absolute objectivity, they can mitigate their influence by remaining reflexive and by making their inherent biases explicit.

Reflexivity is defined by Gerrish and Lathlean (2015) as critical self-reflection and Maxwell (2008) suggests reflexivity may be operationalised through the use of reflective memos. For example, Walker, Read and Priest (2013) used memos in a mixed methods grounded theory study involving semi-structured interviews and a casenote review (n=150) to investigate end-of-life care preferences. Walker, Read and Priest (2013) reported that a daily reflective journal was used to note the research process and to critically evaluate the researcher's thoughts and observations on the study. They report that the reflexive method not only enhanced trustworthiness but also helped to review study progress, plan further data collection, evaluate the researcher's skills and identify areas for improvement.

Therefore in this study tools were used to strengthen confirmability by ensuring the researcher remained aware of her influence on the study. The tools were a coding journal, coding memos and reflective memos. Reflective memos were particularly used when the researcher encountered personal bereavements during data collection and analysis and this is addressed in 5.17.10. The tools were used to record decisions and progress and reflect on the researcher's viewpoint.

To complete this chapter, ethical issues are now considered.

3.12 Ethical issues

Death and dying are sensitive research topics (Johnson and Clarke, 2003) because their discussion may be distressing. Pleschberger et al. (2011) therefore identify bereaved people as a potentially vulnerable population, requiring additional efforts from researchers to protect participants' rights and interests. This study was conducted in accordance with the ethical principles of the Declaration of Helsinki (World Medical Association, 2013) and was subject to ethics, clinical governance and information governance review as required by the national research governance framework (Scottish Executive Health Department, 2006).

In other words, the protection and wellbeing of participants was of prime importance. There were arguably four categories of individuals who required safeguarding: the bereaved relatives and healthcare professionals who participated in interviews, the patients whose casenotes were reviewed and the researcher herself. According to Downie & Calman (1987) and Beauchamp & Childress (2009) ethically conducted research must demonstrate beneficence, non-maleficence, respect for autonomy and justice. These principles are now considered in relation to this study and its participants.

3.12.1 Beneficence

Beauchamp & Childress (2009) define beneficence as a contribution to the welfare of individuals, and argue that taking part in research should benefit subjects. There is some evidence that taking part in end-of-life research may modestly benefit bereaved participants. Seale (1998) suggests that bereaved people use research interviews as part of a mourning process, to understand the death or to affirm their social role. Pleschberger et al. (2011) found evidence of this in their reflective review of six qualitative and mixed method studies on end-of-life care, conducted in Belgium, Germany, Netherlands and UK. Some participants believed that speaking to researchers eased loneliness, afforded a chance to give feedback or allowed the opportunity to seek information. In the study reported here it was hoped that participants, whether healthcare professionals or bereaved relatives, would benefit similarly from discussing their experiences.

3.12.2 Non-maleficence

Non-maleficence refers to the obligation on researchers not to harm or exploit participants (Beauchamp and Childress, 2009). In this study the most obvious potential harm was that of emotional distress for participants. Therefore in addition to reviewing literature, the researcher consulted at local, Scottish and UK levels with clinicians and stakeholders, academics and researchers in bereavement care to ascertain best practice in bereavement interviewing. Consultees advised that:

- Relatives might not be distressed by interviews and might indeed find it beneficial to talk about their loss
- Relatives who did not want to participate could choose not to take part
- Making contact within three to six months of bereavement was deemed acceptable in UK bereavement research.

3.12.2.1 Non-maleficence – preparing for the study

Measures to ensure non-maleficence at various points in the research process have been described. In the study setup phase, Parkes (2006) stresses that researchers must have an understanding of bereavement and know about sources of help and support for participants. Further, researchers investigating potentially distressing topics such as end-of-life care must be trained in interviewing techniques. Last, the researcher should be supervised by someone with experience of palliative care research. Steps to address these points in this study are outlined in 5.11, 5.12 and 5.15.4.

Several studies on bereavement (Teno, Casey, Welch and Edgman-Levitan, 2001; Davies and Clarke, 2005; Hynson, Aroni, Bauld and Sawyer, 2006) in Australia, the US and the UK used letters to make initial contact with participants. Hynson et al. (2006) checked this approach in qualitative interviews with 45 bereaved Australian parents. The parents reported that the approach by letter seemed sensitive and appropriate and did not cause distress. Hence letters were used for initial contact by the researcher in the study reported here.

3.12.2.2 Non-maleficence – conducting interviews

Other recommendations relate to the interview itself. Sque (2000), Pleschberger et al. (2011) and Ashton (2014) all report that it was common for participants to cry in interviews on end-of-life issues. Where participants become distressed Parkes (2006) suggests it is good practice to offer to stop, re-arrange or abandon interviews.

Hoffmann (2007) suggests researchers support distressed or angry participants by changing position, watching and mirroring participants' body language and level of emotional response or by offering to end the interview. Nevertheless it is interesting to note that in several studies, distressed participants never accepted offers to terminate interviews (Sque, 2000; Pleschberger et al., 2011; Ashton, 2014). Pleschberger et al. (2011) suggest the presence of a third party to support the participant, arguing this may level the power balance within interviews and enhance a sense of security, particularly for interviews conducted in the homes of elderly or other vulnerable interviewees. In responding to participant distress, Pleschberger et al. (2011) emphasise the need for reflexivity on the part of the researcher, to assess what is happening and make ongoing intra-interview ethical choices about emotional boundaries.

The consultation with other UK researchers (see 3.12.2) also elicited a protocol for avoiding or handling distress in bereavement interviews [Addington-Hall et al. (2005), unpublished] which incorporated several of the above points and which was adopted for this study:

- Offering possibility of having a friend or relative present at interview
- Emphasising at outset that the interview is voluntary and participant may withdraw at any time.
- If the participant becomes distressed during interview, offering to take a break or stop the interview altogether.
- Actively listening to the individual's concerns. Providing telephone numbers of voluntary organisations, such as CRUSE (a bereavement support charity) and The Samaritans (a telephone support charity), if appropriate.

- Advising the participant to contact their GP, or exploring the possibility of contacting the participant's GP on their behalf.
- Seeking advice, support and direction from supervisors in order to ensure that appropriate action is taken.

3.12.2.3 Non-maleficence – summary

Sque, Walker and Long-Sutehall (2014) tested a framework for good ethical conduct in bereavement studies, addressing issues such as recruitment, interview and follow-up. Sque, Walker and Long-Sutehall (2014) reviewed four UK studies on end-of-life care and organ donation published between 1996 and 2006. They identified practices approved by ethics review and used to minimise participant distress, summarising these into a framework. The framework was then applied in their study using qualitative interviews (n=43) to investigate family experiences of organ donation. The researchers asked participants how distressing they found it to take part. More than one third (39%) said it was not distressing and just over half 58% reported a little distress. Sque, Walker and Long-Sutehall (2014) concluded that it is possible to recruit, interview and support participants in ways that minimise distress.

While care was taken to avoid distressing bereaved relatives, it was recognised that healthcare professionals too suffer bereavement. Therefore the issue was addressed sensitively with both participant groups.

3.12.3 Respect for autonomy

Researchers demonstrate respect for the autonomy of their participants by seeking their informed consent, usually written, to take part in studies (Polit and Beck, 2013). Beauchamp and Childress (2009) identify veracity, or full and truthful disclosure about the nature of research as a necessary precursor to the giving of informed consent. Additionally, avoiding actual or implied coercion is key to respecting the autonomy of participants (Gerrish and Lacey, 2010). Therefore researchers are required to provide full information about their study in a format which potential recruits understand, allow enough time for

potential recruits to decide if they wish to participate, and obtain written informed consent prior to participation (Scottish Executive Health Department, 2006).

There were additional considerations because this study included a potentially vulnerable group i.e. bereaved relatives. Pleschberger et al. (2011) suggests that gatekeepers can act as intermediaries between researchers and bereaved populations. Gatekeepers can introduce the study to potential participants and distribute information about the research, thereby minimising perceptions of coercion and enabling relatives to decline freely if they wish. Gatekeepers were therefore used in this study. Also to minimise coercion, Sque, Walker and Long-Sutehall (2014) suggest that in research with bereaved relatives it is good practice to allow potential recruits at least 10 days to decide whether to participate. Hence a similar time span was adopted in this study.

A further group to consider were any third parties who supported bereaved participants in interviews. Pleschberger et al. (2011) suggest that researchers need to judge whether informed consent is required in such cases. They used a creative approach, gauging the extent to which the third party was observing or participating in the interview in order to determine the requirement for consent. A similar approach to third parties was adopted in this study.

The researcher also needed to respect the autonomy of deceased patients whose casenote data were reviewed in this study. Clearly these patients could not consent to the researcher accessing their notes. Scottish Government policy states that access to the data of deceased patients required approval from Caldicott information guardians (The Scottish Government, 2010). Caldicott information guardians are senior clinicians or administrators appointed to oversee access to patient data. Approval to use anonymised casenote data was obtained accordingly (see 4.1.5.2).

Maintaining confidentiality and privacy are also linked to respecting autonomy (Beauchamp and Childress, 2009). Where participants are known to researchers, the confidentiality of those participants' data may be maintained by:

- using anonymised identification codes to store, analyse and report data
- storing data securely

- ensuring data are reported in a way that does not allow identification of participants
- e.g. reporting aggregate not individual sample characteristics (Polit and Beck, 2013).

Accordingly, these principles were followed in this study.

3.12.4 Justice

According to Downie and Calman (1987), respecting the autonomy of individuals also involves the principle of justice, i.e. treating individuals or social groupings fairly. Eckstein (2003) argues that dying patients are often excluded from research in order to protect them from the burden of participation, thereby inadvertently but unfairly excluding them from the benefits of participation. Further, Addington-Hall, Bruera, Higginson and Payne (2007) identify that because of practical difficulties in recruiting dying patients into studies (see 3.7), the dying are an under-researched social group. Therefore by exploring care of the dying, this study addressed exclusion, honouring the principle of justice.

3.12.5 Effect on the researcher

In their review Pleschberger et al. (2011) noted that working on bereavement affected researchers negatively. Although experienced, several still reported feeling sadness, worry, or shock, to an extent which hampered their analysis.

Other studies have indicated these problems may be particularly marked for nurse researchers. For example Johnson and Clarke (2003) conducted qualitative interviews with ten researchers who were investigating sensitive topics. Five of the researchers were nurses; the remainder were medical sociologists and teachers. All the researchers reported anxieties about inexperience and lack of training. Worries about role conflict were most commonly reported by the nurses in the study. Their main concerns were maintaining a neutral observational stance while protecting participants adequately, and managing the expectations of participants who knew the researchers were nurses. Hence Johnson and Clarke (2003) emphasised the need for training, supervision and support for researchers investigating sensitive topics, particularly nurse researchers accustomed to acting in a

caring role. This point is also stressed by Ashton (2014) who found interviewing as a lone nurse researcher was emotionally burdensome but that debriefing was an important source of support.

The above points were considered when planning researcher support in the study which is now reported.

Chapter 4 – Casenote review

In this chapter the conduct and findings of the casenote review are presented. Since both the casenote review and the qualitative interviews were carried out in the same study sites, the first part of the chapter presents background information on the sites. Additionally, ethics and governance permissions for both parts of the study are intertwined and so are reported together as background. Thereafter, the sampling, piloting, data collection and analysis of the casenote review are reported. Findings are then presented in relation to the research questions and summarised at the end of the chapter. Discussion of the casenote review findings is located in Chapter Six.

4.1 Study background

4.1.1 Study sites

Suitable hospital study sites were selected purposively. Sites were required to have stroke units where an end-of-life care pathway was used, to be open to research and to have a sufficient throughput of patients to gain a sample for the study. Acute and combined stroke units were included in order to investigate care given to the widest possible range of patients. To control study costs, sites also had to be within travelling distance of the researcher's university i.e. around the central belt of Scotland. A mix of hospital type and urban and rural populations was sought.

Lead clinicians (senior doctors) at potential sites across central Scotland were identified. Lead clinicians (n=5) at four hospitals agreed to support the study at their local site and were invited to become study grantholders. The NHS in Scotland is administered via 14 regional health boards. Cross checks against 30-day mortality figures by health board from NHS Scotland (Information Services Division Scotland, 2009) suggested that the four study sites would yield an adequate sample size. In follow-up field work (see 3.9.5.2) the researcher visited the sites and spoke to senior charge nurses to check that the NHS Scotland 30-day mortality figures accurately reflected stroke unit death records, and to establish that an end-of-life care pathway was in use.

The sample of sites covered three Scottish health boards, of which one served the largest and sickest urban population centre in Scotland and two served mixed urban and semi-rural populations. In the largest health board, two hospital sites were used. In all, three city teaching hospitals and one district general hospital were included. The units were classed either as acute stroke units (ASU) or combined ASU/stroke rehabilitation units (Scottish Stroke Care Audit, 2011).

Descriptive details of the sites are presented in Table 4-1 although to protect their anonymity, identifying features are removed or reported within an indicative range. For this reason, sites are not labelled in Table 4-1. After Table 4-1 the study sites are referred to as Sites A, B, C and D.

Table 4-1 Profile of study sites at study commencement

Site characteristics	Study site	Study site	Study site	Study site
Number of stroke beds ¹	14 – 38 per site			
On-site thrombolysis service	Yes	No	Yes	Yes
Senior medical cover	7 days	Weekend team	Weekend team	7 days
Acute stroke admissions in 2010 ¹	310-330	450-490	270-315	480-520
Deaths within 30 days of stroke (2008) ² (including off-site beds)	64	78	67	122
Mean length of stay ¹ (including off-site beds)	24-26	24-26	19-20	30-33
Number of trained nurses/whole time equivalent (WTE)	13	22	13	19
Number of untrained healthcare assistants /WTE	7	29	9	9
Number of speech and language therapists	1	2	3	3
Number of stroke consultants	6	5	3	3
Type of end-of-life care pathway used	LCP	LCP	LCP	LCP
Date LCP introduced to unit	June 2011	Sept 2010	July 2010	Oct 2010
Version of LCP used	11	11	11	12
Routine follow up of bereaved relatives	No	No	No	Yes

¹ Scottish Stroke Care Audit. (2011). Scottish Stroke Care Audit 2011 National Report: Stroke Services in Scottish Hospitals. Edinburgh.

² Information Services Division Scotland. (2009). Stroke: Survival for 30 days after emergency admission. Scottish Clinical Indicators on the Web.
<http://www.indicators.scot.nhs.uk/TrendsJuly09/Stroke.html>

4.1.2 The LCP and study sites

The Liverpool Care Pathway (LCP) was the end-of-life care pathway used in all sites. Consequently the term 'LCP' is used from this point on, rather than the more generic 'end-of-life care pathway' when discussing the tool used in study sites. The LCP was relatively new to the study sites. Educational activities to support implementation had taken place within the previous year and ward 'LCP champions' were in place, so the profile of the LCP was already raised before the study began.

4.1.3 Funding

The study was funded by Chest Heart & Stroke Scotland (R11/A133). The researcher was employed as a research assistant to the study.

4.1.4 Pre-study visits

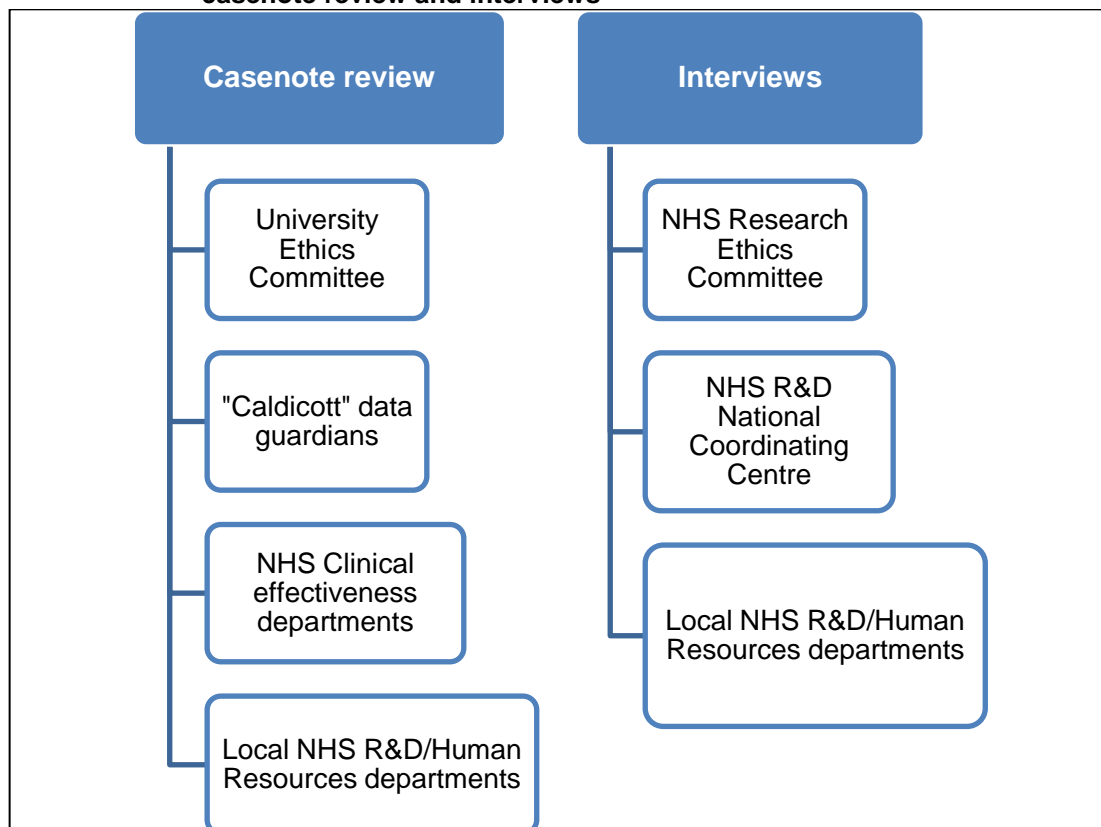
In addition to the field work, two to three months before the study began the researcher made contact with the clinical teams in each study site by visiting the senior charge nurses, trained and untrained nursing staff and wards clerks. Written information about the study was left for staff to read. In two sites the researcher was known to the staff from previous studies. The lead clinicians were already involved but the researcher introduced herself to other senior doctors based at the study sites. These visits helped to build working relationships and understanding about the study.

4.1.5 Ethics committee and other governance approvals

Several processes were involved in gaining ethics and management approvals for this study. The processes ran concurrently and the organisations and departments from which approvals were required for each study component are shown in Figure 4-1.

NHS Research Ethics Committee approval and NHS Research and Development (R&D) approval was required for the qualitative interviews and questionnaire. Separate approvals were required for the casenote review and these are reported in 4.1.5.2.

Figure 4-1: Diagram showing the bodies from which approvals were required for the casenote review and interviews



4.1.5.1 Approvals for interviews

Ethics approval (11/WS/0024) for the qualitative interviews and questionnaire was granted on 18th August 2011 (see Appendix 3) by the West of Scotland Multicentre NHS Research Ethics Committee. Approval was subject to minor changes to the consent form, confirmation that clinicians would make the first approach to patients or families about the study and confirmation that the researcher would inform participants about NHS complaints procedures if required. The Committee directed that it was unnecessary to notify GPs of participants' involvement in the study. The researcher made the required alterations and confirmed these to the Committee (Appendix 4) who then issued final approval (Appendix 5).

NHS R&D permissions were granted via the NHS Research Scotland Permissions Coordinating Centre and Site Specific Investigation applications in September 2011 for all sites (Appendix 6).

4.1.5.2 Approvals for casenote review

In June 2011 the NHS R&D service directed that the casenote review was audit and hence outside the NHS Research Ethics Committee remit (see Appendix 7). The researcher therefore obtained approval for the casenote review from the University of Glasgow College of Medical, Veterinary and Life Sciences Ethics Committee in September 2011 (FM08127) (see Appendix 8). Following the issue of honorary contracts or Letters of Access, approvals from Caldicott data guardians (Appendix 9) and clinical effectiveness managers were also obtained in each health board area. Caldicott data guardians are senior clinicians or administrators appointed to oversee access to patient data (The Scottish Government, 2010).

There were some delays with Caldicott guardian and clinical effectiveness approvals. The delays necessitated a staggered start to data collection and limited the sampling for qualitative interviews in one site (see 5.7.3.2) while lengthening the overall data collection period for the casenote review.

4.1.6 Study adoption

The study was adopted by the Scottish Stroke Research Network (SSRN) in November 2011, co-registered with the Age & Ageing and Stroke NIHR Research Networks and added to the UK Clinical Research Network Portfolio Database (UKCRN ID 11143). This benefited the study by raising its profile and the SSRN provided access to a medical statistician for advice.

The casenote review is now presented in the rest of this chapter.

4.2 Aims of the casenote review

- To describe and compare characteristics of stroke patients on an end-of-life care pathway and characteristics of stroke patients who die but who are not on an end-of-life care pathway

- To explore preferred place of care for patients on end-of-life care pathways in acute stroke units
- To explore outcomes of end-of-life care pathway use
- To describe the context of end-of-life decision-making in this study.

4.3 Research questions

The casenote review was used principally to answer the first and third research questions, namely:

1. Are patients with fatal stroke who are judged to require an end-of-life care pathway different (in terms of age, gender, stroke type/severity or comorbidity) from patients with fatal stroke who die without introduction of an end-of-life care pathway?
3. What is the outcome for stroke patients on an end-of-life care pathway transferred from stroke unit to another care facility?

Additionally, although the second research question on perceptions would mainly be addressed via the qualitative interviews, quantitative casenote data were also explored to help answer subsections of that research question:

- 2a: How is the clinical decision made to place a stroke patient on an end-of-life care pathway?
- 2b: What is the experience of end-of-life care pathway use for stroke patients, families and the multidisciplinary team?

As stated in 4.1.2, the end-of-life care pathway used in study sites was the LCP. Hence the casenote data were used to investigate how or if clinicians documented expectations of dying and when decisions were taken to use the LCP. Patterns of LCP use were also explored, for example duration of LCP use was measured. Additionally, aspects of LCP-based care such as symptom management were measured and contrasted with non-LCP end-of-life care.

Further, as this was a mixed methods study casenote data are also used to provide a “thick description” (see 3.11.2.2) of the study sites, patient characteristics and key features of the end-of-life care provided.

4.4 Design

A descriptive correlational design was used to review casenotes and investigate predictors of care pathway use and outcomes. In each site, casenotes were reviewed for consecutive patients for whom the LCP was used, or who died without the LCP being used to support their care. Use of the LCP was investigated as a primary process measure. Death was measured as a secondary outcome.

It was anticipated that a small group of stroke patients on the LCP might be discharged for end-of-life care in another setting. In such cases, it was planned that the researcher would follow-up by telephone to establish the patient’s outcome.

4.5 Justification for sample size

As outlined in 3.9.5 the literature indicated that the sample size should exceed 30 in each group i.e. two patient groups, cared for with or without an end-of-life care pathway. The final sample size was balanced against the practical restrictions of having one data collector and multiple study sites.

Scottish NHS figures (Information Services Division Scotland, 2009) reported 64-122 deaths in the study sites in 2008 (see Table 4-1). However, these figures included deaths in off-site beds. Therefore in October 2010 a field visit was made to one site (Site B) to check number of deaths on-site in the previous year. Checks on the unit’s death certificate books showed 47 deaths for the period 30th November 2008 - 1st December 2009, of which 30 had stroke listed either as primary cause of death or secondary cause where stroke was the reason for admission. Conversations with charge nurses in the other sites confirmed similar figures. Therefore a sample of 25 casenotes per site with a total sample of 100 casenotes was both achievable and manageable in terms of data collection. Statistical advice was

sought as to whether the estimated number was sufficient for analysis and the medical statistician agreed the proposed sampling strategy.

Additionally, it was planned that data on secondary outcome would be collected for a subgroup of 15 stroke patients from all study sites who were placed on the LCP and subsequently transferred to care setting.

Criteria for inclusion were: clinical diagnosis of stroke; cared for in ASU at study site; LCP used and/or died in unit of study; aged 18 or more. Casenotes were excluded in cases of subarachnoid haemorrhage or cerebral metastases as recommended by Warlow et al. (2008), because these conditions have different presentations and clinical management from those of ischaemic or haemorrhagic stroke.

The medical statistician agreed that the proposed sampling framework and analysis were acceptable.

4.6 Access

The researcher left her contact details with the senior charge nurses and ward clerks in each site, and phoned or visited at least twice weekly during the casenote review period, maximising the likelihood of identifying all suitable casenotes. The clinical team i.e. nurses and ward clerks notified the researcher when the LCP was used for a patient or when a patient died without the LCP being used. This avoided the researcher having to check every patient's casenotes at each visit, and ensured no casenotes were missed. At the end of the care episode the researcher reviewed the casenotes before they were filed off-site.

Thus casenotes were usually identified prospectively but reviewed retrospectively once at the end of the care episode. Most cases were notified to the researcher in advance.

4.7 Data collection

Data for the casenote review were collected between November 2011 and June 2012.

4.7.1 Relationship with existing clinical audits

As stated in 4.1.2, the end-of-life care pathway used in study sites was the LCP. Therefore initially the researcher planned to request access to routinely collected local LCP audit data as well as to Scottish Stroke Care Audit (SSCA). This would have made data collection considerably quicker, but it emerged that there was no standard national LCP audit system. Audit practices varied across study sites and audits were conducted infrequently. Further, the SSCA advised that making the required application to their Privacy Advisory Committee would cause delay. Given the small number of casenotes involved, they advised it would be more straightforward to obtain data directly from the casenotes. Therefore the researcher developed a data collection tool and reviewed casenotes manually. This approach had the advantage that additional variables identified in the literature review could be added to the data collection tool. In order to maximise agreement with SSCA and LCP audit methods, the researcher spent time observing a SSCA auditor collecting data and used the SSCA data definitions (Scottish Stroke Care Audit, 2010) when collecting casenote data. The researcher also contacted LCP auditors and clarified their data collection standards.

4.7.2 Data collection tool

Items were adopted from the SSCA tool (n=18), the LCP audit tool (n=27) or identified from the literature review (n=33). The completed tool comprised 78 variables (see Appendix 10). The variables were grouped into categories that covered:

- Demographic information (age, sex)
- Comorbidity, measured using the Charlson Comorbidity Index (Goldstein et al., 2004)
- Current clinical presentation, diagnosis and acute stroke management
- Physical function before stroke and around time of stroke onset (Counsell et al., 2002)
- Care items and decisions including use of LCP, resuscitation and feeding
- Communication with the patient, family and GP

- Clinical outcome (death or discharge).

4.7.3 Pilot work

The data collection tool was piloted with four sets of casenotes in the two stroke units in Health Board 1 where approvals were granted without undue delay. Because of time constraints, piloting took place in only two units to expedite data collection, rather than wait and pilot across all sites, as delays were anticipated with the remaining approvals. The anonymised pilot data were also entered into the statistical analysis package to check the coding system the researcher had created. The researcher had experience of casenote data extraction and this was advantageous in designing the tool, speed of access and recording of data.

4.7.4 Issues arising from piloting the casenote review tool

The pilot work confirmed that the tool appeared to perform as intended i.e. it covered the main issues of end-of-life stroke care. Minor typographical changes were required for clarity of data retrieval and statistical coding. The item on resuscitation was split to reflect formal and informal casenote entries, because piloting showed that resuscitation decisions were occasionally written about in the notes without completion of the formal document. Items on enteral feeding were added. Items on discontinued treatment were condensed into two new categories, in order to capture decisions not to commence (i.e. withhold) treatments as distinct from decisions to stop (i.e. withdraw) treatment or investigations.

The final version of the data collection tool is shown in Appendix 10.

4.7.4.1 Using the Charlson Comorbidity Index

Piloting the tool highlighted the need to clarify the Charlson Comorbidity Index coding for renal disorders. Initially it was unclear whether to record acute kidney injury as comorbidity. The researcher reviewed relevant literature and discussed the issue with academic supervisors. Initially the researcher considered that acute kidney injury was a transient condition that might resolve. Charlson, Pompei, Ales and MacKenzie (1987) reported that they excluded “conditions which had completely resolved (i.e. history of pneumonia)” (p375) by hospital discharge. Nevertheless, they did not make clear whether

they would include a resolved episode of acute kidney injury in their category of moderate renal insufficiency. On the other hand, in a study of 558,032 US hospital discharges where acute kidney injury was included in discharge records, the presence of an ICD-9 code for acute kidney injury was associated with longer hospital stay, increased mortality and greater need of post-discharge care (Liangos et al., 2006). Further, in their study validating the Charlson Comorbidity Index in a stroke population, Goldstein et al. (2004) included all ICD-9 renal disease codes as moderate/severe renal disease. Therefore after review and discussion, acute kidney injury was included in Charlson scores for the casenote review.

4.7.4.2 Clarifying anticipation of death

Piloting the tool also highlighted difficulties with recording the item adapted from the LCP audit, ‘Was the end-of-life anticipated?’ The item was included because it was thought to be a reasonable indicator for non-use of the LCP. However, operationalising the variable required clarification. Pilot work showed that some clinicians documented a belief that patients might be in their last illness yet did not expect them to die imminently. The researcher therefore adopted the General Medical Council’s (2010) definition of imminent death as being “expected within a few hours or days” (p8). Accordingly, the question was modified to include one item on general expectation and an item specific to anticipation of imminent death:

- Was end-of-life considered to be a possibility in relation to this stroke event?
- Was end-of-life anticipated within the next hours or days?

4.7.4.3 Casenote review – time of death

The fact that death has occurred should be verified soon afterwards by a doctor, paramedic or senior nurse with suitable training (Home Office, 2004). This is a separate procedure from certifying death and death certificates may be issued hours or days after death (Home Office, 2004). During the pilot and full data collection period, no nurses verified deaths in casenotes; instead, they typically recorded that death appeared to have taken place and contacted a doctor to verify their assessment. Accordingly, for the casenote review, the time of death was taken as the time when death was verified by a doctor.

4.8 Data handling and storage

Data were collected by the researcher and stored in accordance with the 1998 Data Protection Act (Legislation.gov.uk, 2015), the NHS Confidentiality Code of Practice (NHS Scotland, 2003) and university guidance (University of Glasgow, 2015). These stipulate that data should be stored securely in an anonymised form and that data should be stored only for as long as needed. Accordingly, anonymised data were recorded on paper copies of the data collection tool. Confidentiality was maintained by using unique anonymised case identifier numbers for each paper record. The completed data collection forms were stored securely in a university office. Paper and electronic data (4.9) were retained securely until completion of the research, to enable reporting of results, publication in peer reviewed journals, and completion of the researcher's PhD.

4.9 Data entry

The anonymised data were coded and entered into SPSS 19 for analysis, using the unique case identifiers. Data were entered on a password-protected university computer accessible only by the researcher. Data from pilot work were excluded from analysis.

4.9.1 Coding

Data were coded and entered into SPSS as numeric variables. Most data were categorical and were coded numerically in ascending order from zero. For example, stroke pathology was coded:

0=ischaemic

1=haemorrhagic.

Age was entered as a continuous variable. Charlson Comorbidity Index scores were entered both as continuous ordinal variables and as dichotomised categorical variables, where 0-1 was scored as low comorbidity and 2-9 as high comorbidity. Dates and times were entered using the SPSS date and time functions.

4.9.2 Generating Charlson Comorbidity Index scores

A Microsoft Excel macro file (Hall et al., 2004) was used to generate a Charlson Comorbidity Index score for each casenote. The macro's option to adjust for age was not selected because age was analysed separately. In line with the work of Charlson et al. (1987) and Goldstein et al. (2004), comorbidities recorded at admission and those diagnosed during the care episode were included. Additionally, as per Goldstein et al. (2004), cases with diabetes and kidney disease were assigned to the 'diabetes with end organ damage' category to avoid double counting. The researcher also adopted the approach of Goldstein et al. (2004) in excluding cerebrovascular disease and hemiplegia from comorbidity scoring. This was because stroke was the primary condition for evaluation and excluding stroke variables from comorbidity scoring avoided a double-counting bias. Rather, stroke variables were recorded and analysed separately. Once generated with the macro, the Charlson Comorbidity Index scores were entered into SPSS.

4.9.3 Missing data

Some data were not recorded in casenotes and were therefore categorised as missing. For example, for the case mix variables collected, 14 casenotes had missing data items on pre-stroke independence and upper limb power, ability to walk independently or living alone pre-stroke. The missing data were excluded from analysis.

4.10 Data analysis

A statistical analysis plan was developed in advance of analysis and agreed with academic supervisors and a medical statistician.

4.10.1 Statistical analysis

Descriptive statistical analysis using SPSS 19 was performed on demographic and clinical variables. Distributions of continuous variables were checked using box plots, skewness and kurtosis calculations and histograms. For continuous variables, median values and ranges are reported. For categorical variables, frequencies and percentages are reported.

Descriptive statistics were generated initially, checking for any differences in characteristics between sexes. Thereafter analysis focused on use of the LCP.

Use of the LCP was studied as a primary process measure. Death was measured as a secondary outcome. There were no significant differences ($p=0.486$) in rates of LCP use across study sites (Table 4-2). Therefore data from all sites were pooled and interpreted collectively.

Table 4-2 Cross tabulation of LCP use, by study site

Study site	Was LCP used?		Total
	No	Yes	
Site A	9	16	25
Site B	8	17	25
Site C	13	12	25
Site D	11	14	25
Total	41	59	100

Means, medians and frequencies of variables were compared between the subgroups of LCP cases and non-LCP cases. Associations between variables and LCP use were tested. The time lapse in days between LCP initiation and death as a secondary outcome was calculated by subtracting date of LCP commencement (if relevant) from date of death.

The researcher was aware that given the small sample, inferences between the sample and the wider population should be drawn with caution. Yet there was reason to believe that the sample was representative of the wider Scottish end-of-life stroke population in terms of age and sex and this is discussed further in 6.8. Therefore the researcher also used inferential statistics to investigate relationships between variables and whether certain variables were predictive of LCP use. None of the data were normally distributed so non-parametric tests were used. The Mann-Whitney U test was used to test for differences in continuous variables between two groups; the Kruskal-Wallis test was used to detect differences among three or more groups. For categorical variables the Pearson Chi-Square test was used to test for differences among groups and where expected counts were less than five, Fisher's Exact Test was used. Statistical significance was set at 0.05 (two-tailed).

The researcher accepted that as Stevens (2012) points out, small samples (<100 per group) may suffer from under-powering and be susceptible to Type II error. Hence with the relatively small sample size (n=100) in the casenote review, only large differences between groups were likely to be detected statistically. Stevens (2012) suggests raising the p-value in small samples in order to avoid Type II errors. On the other hand, multiple statistical tests were also used which Stevens (2012) cautions can increase the likelihood of spurious false positives. To counter the risks of such Type I errors, a statistical correction for multiple testing such as Bonferroni could have been applied, or the level of significance reduced. Pallant (2007) cautions that trying to reduce the risk of a Type I error by making the significance level more stringent can increase the risk of false negatives i.e. Type II errors. On balance, the researcher opted to retain significance at 0.05 (two tailed) and did not apply a correction.

4.11 Results

The planned sample size was achieved. No patient on the LCP was discharged or transferred to another care setting during the casenote review period. Therefore the third research question could not be answered and is not addressed further in this chapter.

Results related to the first research question on differences between patient groups are now considered. A general description of patient characteristics is provided, making comparisons between the sexes. Then differences between the LCP and non-LCP patient groups are reported using the findings of univariate and multivariate analyses. Thereafter results are presented that inform the second research question on recognising dying and experiences of LCP use, and these provide some context for the qualitative interviews reported in Chapter Four.

4.12 Differences between LCP and non-LCP groups (Research question 1)

4.12.1 Patient characteristics

Patients whose notes were reviewed were generally elderly, and the majority had sustained a cerebral infarct. For 68% of the sample this was a first stroke and just under half were recorded as having sustained a severe stroke i.e. total anterior circulatory stroke (TACS). Comorbidity was graded as low i.e. CCI of 0 or 1 for 58%. Women in the sample were significantly older than men. The median duration of LCP use was higher for female patients (see Table 4-3) although there was no significant difference in distribution of duration between groups.

Table 4-3 **Frequencies and distributions of key demographic and clinical characteristics, by sex**

Variable	Total 100 casenotes	Males 46 casenotes n (%)	Females 54 casenotes n (%)	p value*
Study site: Site A	25	11 (23.9%)	14 (25.9%)	0.168
Site B	25	11 (23.9%)	14 (25.9%)	
Site C	25	14 (30.4%)	11 (20.4%)	
Site D	25	10 (21.7%)	15 (27.8%)	
Median age in years [min:max]	82 [47:102]	79 [54:95]	84 [47:102]	0.013
Ischaemic stroke	78	35 (76.0%)	43 (79.6%)	0.809
First stroke	68	31 (67.4%)	37 (68.5%)	0.550
Total Anterior Circulatory Stroke (TACS)	45	17 (36.1%)	28 (51.9%)	0.161
Side of brain affected: Left	50	23 (50%)	27 (50%)	>0.05
Right	40	18 (39.1%)	22 (40.7%)	
Bilateral	6	4 (8.7%)	2 (3.7%)	
Not documented	4	1 (2.2%)	3 (5.6%)	
Median Charlson Comorbidity Index (CCI) [min:max]	1 [0:9]	1[0:6]	1[0:9]	0.592
Dichotomised CCI: Low (0 or 1)	58	28 (60.9%)	30 (55.6%)	0.685
High (2-9)	42	18 (39.1%)	24 (44.4%)	
Adults With Incapacity Act (2000) invoked	19	12 (26.1%)	7 (13.0%)	0.126
LCP used	59	23 (50%)	36 (66.7%)	0.106
Median days duration of LCP use [min:max]	2 [0:23]	1 [0:11]	3 [0:23]	0.018
IQR	1-6 days	1-2 days	1-6 days	
Median length of ASU stay in days [min:max]	11 [1:80]	8 [1:80]	11 [1:75]	0.641

LCP: Liverpool Care Pathway

Statistical tests: continuous variables – Mann Whitney U (2 groups), Kruskal Wallis (3 or more groups); categorical variables – Pearson Chi-Square test (expected counts <5 – Fisher's exact test)

** Statistical significance set at 0.05 (two-tailed)*

Age was one of the Six Simple Variables investigated by Counsell et al. (2002) and is presented above. Of the remainder, significantly more men than women were able to walk without help at first assessment after admission to hospital (see Table 4-4) but the total number was small. Just under half of patients were able to speak on admission to hospital although less than one fifth was fully orientated.

Table 4-4 Five of the Six Simple Variables described by Counsell et al. (2002), by sex

Variable	Total 100 casenotes	Male 46 casenotes n (%)	Female 54 casenotes n (%)	<i>p</i> value [§]
Independent in Activities of Daily Living (ADLs) before current event	59*	29 (63.0%)	30 (55.6%)	0.832
Lived alone in normal place of residence	38 [#]	14 (30.4%)	24 (44.4%)	0.151
Able to talk at first assessment	46	21 (46.7%)	25 (46.3%)	>0.05
Orientated to time, place and person at first assessment	19	12 (26.1%)	7 (13.0%)	0.126
Able to lift both arms off bed at first assessment	27*	15 (32.6%)	12 (22.2%)	0.370
Able to walk without help	7 [‡]	6 (13.0%)	1 (1.9%)	0.047

* missing data=6

[#] missing data =1

[‡] missing data=5

Statistical tests: Pearson Chi-Square test (expected counts <5 – Fisher's exact test)

[§]Statistical significance set at 0.05 (two-tailed)

All patients received a CT scan, 12 received thrombolysis and 63 received aspirin in hospital for secondary prevention. No patient underwent clot retrieval or decompressive surgery post-stroke. Most (n=95) completed a water swallow test shortly after hospital admission. Two patients, of whom one was cared for using the LCP, were referred to specialist palliative care services. Although patients on the LCP had a shorter median length of ASU stay (10.0 days) than non-LCP patients (11.0 days) the difference was not statistically significant. Both groups had the same median total hospital stay of 12.0 days with no significant differences in distributions.

Findings relating to the primary process measure of interest i.e. LCP use are now presented.

4.12.2 Differences between patient groups: univariate analysis

Patients who died on the LCP were compared with those who died not on the LCP by cross-tabulating their demographic and clinical variables with LCP use (Table 4-5). The presence of TACS was used as a marker of severe stroke, since NIHSS scores were infrequently recorded in casenotes (n=11). Patients placed on the LCP tended to be older

($p=0.017$) but differences in stroke severity, comorbidity scores, sex and stroke type between the two groups were non-significant.

Table 4-5 LCP use cross-tabulated with demographic and clinical variables

Variable	Total 100 casenotes	No LCP 41 casenotes n (%)	LCP 59 casenotes n (%)	p value*
Median age in years [min: max]	82.00 [47:102]	80.00 [54:102]	84.00 [47:97]	0.017
LCP use, by sex: Male	46	23 (56.1%)	23 (39.0%)	0.091
Female	54	18 (43.9%)	36 (61.0%)	
Stroke type: Ischaemic	78	34 (82.9%)	44 (74.6%)	0.321
Haemorrhagic	22	7 (17.1%)	15 (25.4%)	
First stroke	68	29 (70.7%)	39 (66.1%)	0.827
Total Anterior Circulatory Stroke	45	18 (43.9%)	27 (45.8%)	>0.05
Median Charlson Comorbidity Index [min:max]	1.00 [0:9]	1.00 [0:6]	1.00 [0:9]	0.360
Dichotomised CCI: Low (0 or 1)	58	26 (63.4%)	32 (54.2%)	0.414
High (2-9)	42	15 (36.6%)	27 (45.8%)	

LCP: Liverpool Care Pathway

Statistical tests: continuous variables – Mann Whitney U; categorical variables – Pearson Chi-Square test (expected counts <5 – Fisher's exact test)

** Statistical significance set at 0.05 (two-tailed)*

4.12.3 Differences between patient groups: multivariate analysis

For all 100 casenotes, binary logistic regression was used to explore if age was an independent predictor of LCP use. LCP use/non-use was entered as the dependent variable; age, sex, TACS/no TACS and Charlson comorbidity score were entered as covariates. Stepwise forward regression was used; the condition for data entry was set at $p=0.05$ and for data removal was $p=0.10$. Under these conditions, age was not a significant predictor of LCP use ($p=0.144$). The influence of primary intracerebral haemorrhage was explored by adding stroke type, dichotomised as ischaemic or haemorrhagic, into the model. Primary intracerebral haemorrhage was not a significant predictor of LCP use ($p=0.321$). Similar modelling was performed for the other prognostic variables reported by Counsell et al. (2002) and shown in Table 4-4 (i.e. pre-stroke independence in ADLs, living alone, speech and orientation, ability to lift arms and ability to walk independently). As with age, these were not significant predictors of LCP use ($p=0.429$).

4.13 Clinical decision-making (Research question 2a)

4.13.1 Recognising dying and indications for LCP use

In all cases (n=59) where the LCP was used, reasons for considering its use were recorded. In 22 cases clinicians cited one clinical indicator, two indicators in 24 cases and in 13 cases three or more clinical indicators were recorded. Stroke severity, clinical trajectory and sepsis were the most commonly cited reasons for considering patients might be dying (see Table 4-6). An explicit diagnosis of dying was noted as a reason for using the LCP in a small number of cases (n=4). Age was never recorded as a factor in deciding to use the LCP.

Table 4-6 Frequency and type of recorded clinical reasons to consider LCP use

Recorded clinical indicator for considering LCP use	Frequency 59 casenotes n (%)
Stroke severity	26 (44.1%)
No progress or improvement despite treatment	14 (23.7%)
General deterioration	14 (23.7%)
Neurological deterioration	13 (22.0%)
Sepsis	13 (22.0%)
Limited prognosis	8 (13.6%)
Cardiovascular deterioration	7 (11.9%)
Presence of co-morbidities	4 (6.8%)
Frailty	4 (6.8%)
Dying	4 (6.8%)
Already receiving “comfort” or “palliative” care	3 (5.1%)
Potential for discomfort if LCP not used	1 (1.7%)
Bowel obstruction	1 (1.7%)

Additionally, in three sites (n=45 casenotes) the standard LCP documentation contained a four point checklist for healthcare professionals to indicate their reasons for using the tool (see 2.4). One casenote was incomplete. Of the 44 casenotes with completed checklists, 44 (100%) indicated the patient was bedbound, 39 (88.6%) that the patient was no longer able to swallow tablets, 31 (52.5%) that the patient was semi-comatose and six (13.6%) that the patient was only able to swallow sips of fluid.

4.13.2 Recognising dying where LCP was not used

The LCP was not used in 41 cases. Of these, deaths were recorded as sudden and unexpected in eight casenotes. In the other 33 casenotes, clinicians recorded that death was generally possible in relation to the current stroke event. Typical phrases referred to “unlikely survival”, “guarded prognoses” or “terminal events”. In a small number of these casenotes (n=7), clinicians recorded more specific expectations that death would occur imminently and considered, but did not use, the LCP for those patients. Recorded reasons for considering LCP use in this group (Table 4-7) were similar to those recorded in casenotes where the LCP was actually used i.e. stroke severity and clinical trajectory were mentioned most frequently.

Table 4-7 Frequency and type of recorded clinical reasons to consider LCP use for non-LCP patients

Recorded clinical indicator for considering LCP use	Frequency 7 casenotes n (%)
Stroke severity	5 (71.4%)
No progress or improvement despite treatment	3 (42.9%)
Limited prognosis	2 (28.6%)
Cardiovascular deterioration	1 (14.3%)
General deterioration	1 (14.3%)
Sepsis	1 (14.3%)
Already receiving “comfort” or “palliative” care	1 (14.3%)

Three of the seven patients died before the LCP could be commenced and one family disagreed with the clinical team, precluding LCP use. Reasons why the LCP was not subsequently used were not recorded in three cases. Of the remaining 26 casenotes, 19 contained phrases indicating that the clinical team felt the patient might die imminently although consideration of LCP use was not recorded.

4.13.3 Exploring patterns of LCP use

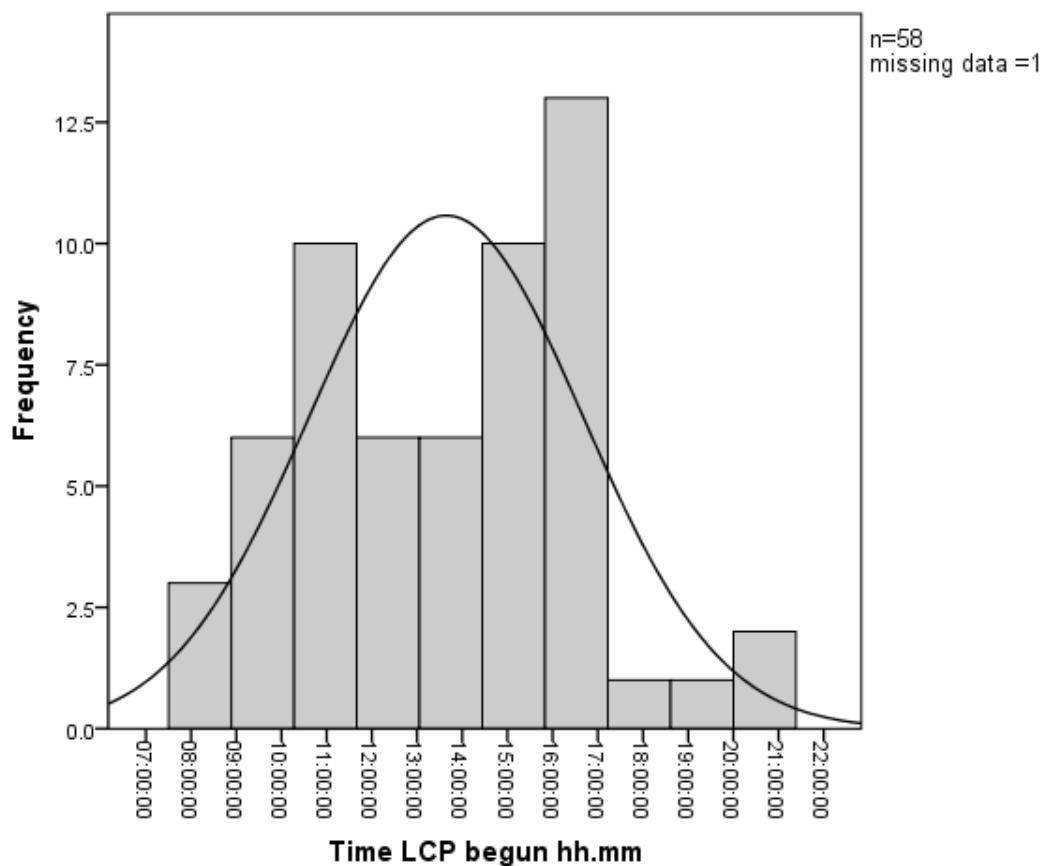
Casenote data collection and interviewing ran concurrently for five months (Feb - June 2012). When the casenote data collection ended in June 2012, qualitative interview data were beginning to show that some participants identified weekend working patterns as a factor in deciding LCP use (see 5.24). Therefore a post hoc analysis was undertaken on the

complete casenote dataset to examine details of decision dates. In keeping with the convergent mixed methods design, findings from the analysis were used to inform an alteration to the qualitative interview schedule (see 5.10.1). The post hoc analysis is now presented.

4.13.3.1 Time of day

Peaks were seen in the times of day when the LCP was most frequently commenced. Decisions were more common late morning and mid-to-late afternoon. The median time for commencement was 1400hrs [interquartile range 1115-1600 hrs] (Figure 4-2).

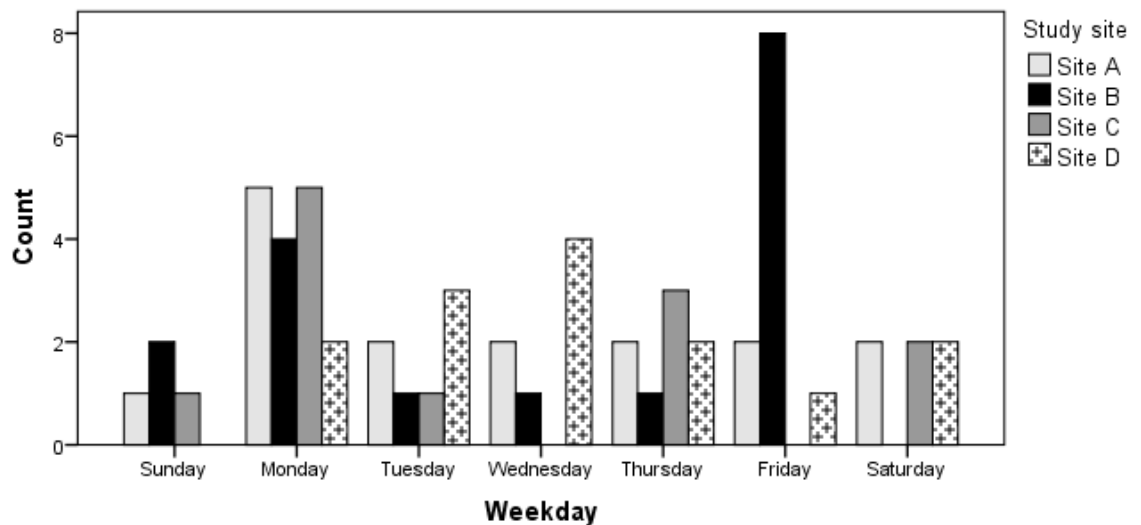
Figure 4-2 Histogram showing median time of day LCP begun (all four study sites)



4.13.3.2 Day of the week

Peaks were also noted in the frequencies of decisions to commence the LCP on particular week days. Frequencies were higher on Mondays in three sites and on Fridays in one site (Figure 4-3). The sample size was judged too small to allow statistical analysis of these differences.

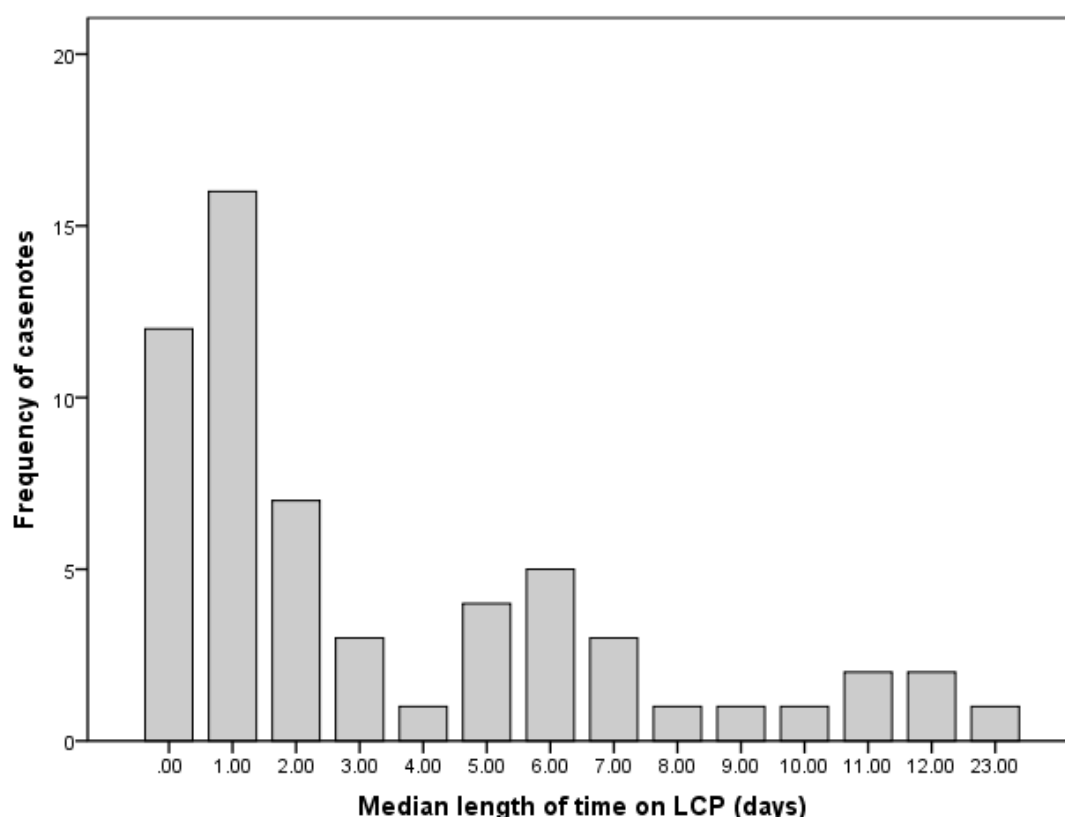
Figure 4-3 Frequency of decisions to use LCP, by weekday and study site



4.13.3.3 Duration of LCP use

The time lapse between the primary process measure of interest i.e. decision to use the LCP and the secondary outcome i.e. death, was measured in order to calculate duration of LCP use. Patients were on the LCP for a median of two days [range 0-23 days, interquartile range 1.0-6.0]. For around one third of patients (n=21, 35.6%) the LCP was used for more than three days and in eight cases (13.6%), for more than seven days (see Figure 4-4).

Figure 4-4 Bar chart showing median LCP duration against frequency of record in casenotes (n=59)



4.14 Experiences of LCP use (Research question 2b): Differences between LCP and non-LCP patients

Patterns of care are reported here for both LCP (n=59) and non-LCP patients, and comparisons are made between the groups where relevant. Eight non-LCP patients died unexpectedly. Therefore their data are included here only for the section on care after death, because the patients were not known to require end-of-life care and it would not be reasonable to include their notes in the analysis of end-of-life care before death. For the remaining non-LCP patients (n=33), clinicians had recorded in each casenote that the patient was generally at risk of dying from the current stroke event (see 4.13.2). Consequently results for these casenotes are presented in the following section and compared with those of LCP patients. Therefore 92 casenotes were examined and reported on in sections 4.14.1 through to 4.14.7.

4.14.1 Care aims, limitations and withholding or withdrawing treatment

Casenotes were examined to identify the explicit aims of care. Additionally, casenotes were checked for evidence of decisions either to withhold i.e. not commence or to withdraw i.e. stop treatments or interventions.

The presence of the LCP in casenotes was taken as explicit evidence that the aim of care was end-of-life care. In the non-LCP group, the aim of care was noted to be “comfort” or “symptom management” or similar in 12 (36.4%) cases and the researcher assumed these terms to be synonymous with end-of-life care.

Around a third of all the included casenotes (n=92) showed evidence of decisions to limit treatment, most commonly to avoid transferring from the acute stroke unit to intensive care units. There were no significant differences between the groups in proportions of casenotes with recorded limits to treatment (Table 4-8).

Table 4-8 Decisions to limit treatment: cross-tabulation of LCP versus non-LCP groups

Recorded treatment decision	Total 92 casenotes n (%)	No LCP 33 casenotes n (%)	LCP 59 casenotes n (%)	<i>p value*</i>
Limits to treatment are recorded	35 (38.0%)	13 (39.4%)	22 (37.3%)	>0.05
Decision not to use ICU	16 (17.4%)	6 (18.2%)	10 (16.9%)	>0.05
Decision not to make neurosurgical referral	10 (10.9%)	4 (12.1%)	6 (10.2%)	0.742
Decision not to use HDU	6 (6.5%)	4 (12.1%)	2 (3.4%)	0.183

ICU: intensive care unit

HDU: high dependency unit

LCP: Liverpool Care Pathway

Statistical tests: Pearson Chi-Square test (expected counts <5 – Fisher’s exact test)

** Statistical significance set at 0.05 (two-tailed)*

Decisions to withhold cardiopulmonary resuscitation (hereafter referred to as DNACPR, or “do not attempt cardiopulmonary resuscitation” orders) are reported in section 4.14.2. Enteral feeding decisions involved both withholding and withdrawing treatment and are discussed in section 4.14.3. Otherwise, decisions to withhold treatment were uncommon. Antibiotics were withheld from two patients (3.4%) on the LCP and two non-LCP patients (6.2%) (p=0.62). Oxygen therapy and glucose monitoring were withheld from one patient

on the LCP. There were no documented decisions to withhold vital sign recordings, non-essential drugs or blood tests in either patient group.

Decisions to withdraw treatments or investigations were significantly more common in LCP casenotes than non-LCP casenotes (Table 4-9). This was expected because the LCP documentation prompted staff to stop certain treatments or investigations (see Appendix 1). However, almost half of the non-LCP casenotes also recorded decisions to stop treatments.

Across both patient groups (n=92) the most common treatment withdrawal decisions involved stopping non-essential drugs, antibiotics, blood tests and clinically-assisted hydration (i.e. intravenous fluids). In the non-LCP group, stopping antibiotics was less common than stopping other interventions like hydration, drugs or vital signs (Table 4-9).

Table 4-9 Documented decision to withdraw treatments or investigations: cross-tabulation of LCP versus non-LCP groups

Treatment type	Total 92 casenotes n (%)	No LCP 33 casenotes n (%)	LCP 59 casenotes n (%)	<i>p</i> value*
Any treatment or investigation	75 (81.5%)	16 (48.5%)	59 (100%)	<0.001
Non-essential drugs	61 (66.3%)	7 (21.2%)	54 (91.5%)	<0.001
Antibiotics	54 (58.7%)	3 (9.1%)	51 (86.4%)	<0.001
Blood tests	54 (58.7%)	2 (6.1%)	52 (88.1%)	<0.001
Clinically-assisted hydration (intravenous/subcutaneous fluids)	48 (52.2%)	9 (27.3%)	39 (66.1%)	<0.001
Vital sign recordings	45 (48.9%)	5 (15.2%)	40 (67.8%)	<0.001
Glucose monitoring	38 (41.3%)	1 (3.0%)	37 (62.7%)	<0.001
Oxygen therapy	6 (6.5%)	0 (0%)	2 (3.4%)	0.084

LCP: Liverpool Care Pathway

Statistical tests: Pearson Chi-Square test (expected counts <5 – Fisher's exact test)

** Statistical significance set at 0.05 (two-tailed)*

4.14.2 Timing of CPR decisions

Seven patients were admitted with a DNACPR order already in place. Decisions to withhold CPR were generally made sooner after admission (Table 4-10) for the patients whose care involved the LCP than for non-LCP patients, although the difference was not statistically significant. Resuscitation decisions were generally made several days earlier

than decisions to use the LCP, which were made a median of 7.0 days after hospital admission (interquartile range 4.0 – 25.0). Therefore the earlier DNACPR decisions seen in LCP cases did not appear to be an artefact of LCP use, because resuscitation was typically decided up to a week before the LCP was commenced.

Table 4-10 Time in days from hospital admission to formal record of DNACPR decision

LCP used?	Median time to DNACPR decision (days)	Minimum time to decision (days)	Maximum time to decision (days)	Interquartile range (days)
Yes	1.0	-313.0	75.0	0.0 – 5.0
No	3.0*	-98.0	50.0	0.25 – 12.0

*missing data n=1

DNACPR: Do Not Attempt Cardiopulmonary Resuscitation

4.14.3 Enteral feeding

Although enteral feeding was considered or provided for a smaller proportion of patients whose care subsequently included the LCP, the differences between LCP and non-LCP groups were not statistically significant (see Table 4-11). Patients whose care subsequently included the LCP were fed for a shorter time and fewer had feeding in progress at time of death, but the differences between the groups were not significant.

For patients on the LCP, enteral feeding ceased a median of 2.5 days [min 0: max 34, interquartile range 2.5-6.25] before LCP commencement. For six patients (42.9%), feeding ceased on the same day as the LCP commenced and for one patient on the LCP, feeding was in progress at the time of death. Enteral feeding ceased earlier before death for patients whose care involved the LCP (see Table 4-11).

Unplanned withdrawal of feeding was more common among the LCP patient group although numbers overall were small. In all casenotes where feeding was withdrawn before death (n=19), reasons for unplanned withdrawal of feeding included accidental tube dislodgement (n=1) or tubes being removed by patients (n=6). Reasons for planned withdrawal of feeding included the presence of aspiration pneumonia (n=3) or gastrointestinal bleeding (n=1), feed not being tolerated (n=1), a change in the aim of care i.e. from intervention to comfort (n=2) or that the patient had deteriorated (n=1). One

casenote in the LCP group recorded that feeding was withdrawn because it was not in the patient's best interests. Three casenotes did not record a reason for stopping feeding or indicate whether there was a clinical plan to withdraw feeding.

Unplanned withdrawals of feeding were higher (n=8, 57.1%) among the 14 LCP patients who had received enteral feeding than among the eight non-LCP patients (n=2, 25.0 %). The numbers were small and the difference was non-significant.

Table 4-11 Clinical decision-making on enteral feeding: cross tabulation of casenote variables in LCP or non-LCP casenotes

Clinical casenote variable	Total 92 casenotes n (%)	No LCP 33 casenotes n (%)	LCP 59 casenotes n (%)	<i>p</i> value*
Enteral feeding considered	n=38	17 (51.5%)	21 (35.6%)	0.816
Enteral feeding administered	n=22	8 (24.2%)	14 (23.7%)	>0.05
Nasogastric route	n=20	7 (21.2%)	13 (22.0%)	>0.05
Median duration enteral feeding in days [min:max]	9 [0:74]	11.5 [0:74]	8.5 [1:29]	0.378
Median time between end feeding and death in days [min:max]	2.5 [0:46]	1 [0:8]	5.5 [0:46]	0.18
Feeding in progress at time of death	n=3	2 (6.0%)	1 (1.7%)	0.292
Feeding withdrawn - planned	n=9	4 (12.1%)	5 (8.5%)	0.350
Feeding withdrawn - not planned	n=10	2 (6.0%)	8 (13.6%)	

LCP: Liverpool Care Pathway

Statistical tests: continuous variables – Mann Whitney U; categorical variables – Pearson Chi-Square test (expected counts <5 – Fisher's exact test)

** Statistical significance set at 0.05 (two-tailed)*

4.14.4 Symptom assessment

Assessment of symptoms was specifically prompted by LCP documentation but not by the standard i.e. non-LCP charts or forms. Table 4-12 shows that significantly more patients in the LCP group were noted to have swallowing difficulties, agitation and restlessness in the last few days of life. Pain, non-specific distress, nausea, vomiting and constipation were noted slightly more frequently for patients on the LCP although not statistically significant and numbers were small. Although symptoms were generally noted less frequently in the non-LCP group of patients, nevertheless the frequency ranking of symptoms were similar in both groups. There were no significant differences between groups in the assessment of

excessive respiratory tract secretions or breathlessness, which affected from one third to one half of patients.

Table 4-12 Frequency of documented symptoms in patients with and without LCP-based care.

Symptom documented in last hours or days of life	Total 92 casenotes n (%)	No LCP 33 casenotes n (%)	LCP 59 casenotes n (%)	p value*
Dysphagia	57 (62.0%)	13 (39.4%)	44 (74.6%)	0.002
Respiratory tract secretions	43 (46.7%)	11 (33.3%)	32 (54.2%)	0.081
Dyspnoea	36 (39.1%)	13 (39.4%)	23 (39.0%)	>0.05
Agitation	30 (32.6%)	5 (15.2%)	25 (42.4%)	0.010
Pain	24 (26.0%)	7 (21.2%)	17(28.8%)	0.465
Distress	14 (15.2%)	4 (12.1%)	10 (16.9%)	0.763
Restlessness	11 (12.0%)	0(0%)	11(18.6%)	0.007
Nausea and vomiting	5 (5.4%)	1 (3.0%)	4 (6.8%)	0.650
Constipation	2 (2.2%)	0(0%)	2(3.4%)	0.535

LCP: Liverpool Care Pathway

Statistical tests: Pearson Chi-Square test (expected counts <5 – Fisher's exact test)

* Statistical significance set at 0.05 (two-tailed)

Action to alleviate and review symptoms was noted in 56 (94.9%) of LCP casenotes and 29 (87.9%) of non-LCP casenotes. Drugs were prescribed *pro re nata*, or as required (PRN), in all LCP casenotes and in 32 (97%) of non-LCP casenotes. Analgaesic drugs were prescribed for pain, sedatives for agitation, anticholinergics for excess respiratory tract secretions and anti-emetics for nausea and vomiting. Morphine was commonly prescribed to alleviate both pain and breathlessness. There were no significant differences in frequencies of analgaesic prescriptions between LCP and non-LCP casenotes, otherwise prescribing rates were significantly higher in LCP casenotes (Table 4-13).

Table 4-13 Cross-tabulated frequency of PRN prescribing in casenotes with and without the LCP

Type of drug prescribed	Total 92 casenotes n (%)	No LCP 33 casenotes n (%)	LCP 59 casenotes n (%)	p value*
Analgaesic	90 (97.8%)	31 (93.9%)	59 (100%)	0.126
Sedative	76 (82.6%)	18 (54.5%)	58 (98.3%)	<0.001
Anti-cholinergic	73 (79.3%)	18 (54.5%)	55 (93.2%)	<0.001
Anti-emetic	56 (60.9%)	12 (36.4%)	44 (74.6%)	<0.001

LCP: Liverpool Care Pathway

Statistical tests: Pearson Chi-Square test

** Statistical significance set at 0.05 (two-tailed)*

Medication for symptom control was most commonly prescribed via the intermittent subcutaneous route in 88.1% (n=52) of casenotes using the LCP and 78.8% (n=26) of non-LCP casenotes (not significant). There was no significant difference between groups in numbers of patients who received PRN medications. In the LCP group 53 (89.8%) and in the non-LCP group 28 (84.8%) of casenotes recorded PRN medication administration.

4.14.5 Communicating with primary care

In three study sites, standard LCP forms instructed staff to notify GPs that their patient was dying. For casenotes involving the LCP in those sites (n=45), it was recorded that GPs were notified about 18 patients. In the fourth site notifying GPs was not specified on the standard LCP proforma (n=14 cases) and no GPs were contacted. Across all sites, no GPs were notified that non-LCP patients were dying.

4.14.6 Communicating with patients and families

Barriers to communicating with patients in their last few days of life were noted. Overall ten patients were noted to be deaf or hard of hearing, eight in the LCP group and two in the non-LCP group. The majority of patients in both groups were noted to have periods of unconsciousness in the last few days of life: 51 (86.4%) of LCP patients and 24 (72.7%) of non-LCP patients. Additionally more LCP patients (n=18, 30.5%) experienced periods of confusion in their last few days than non-LCP patients (n=4, 12.1%) although this was not

statistically significant. Significantly fewer ($p<0.001$) patients on the LCP were noted to be dysphasic or aphasic ($n=7$, 11.9 %) than those not on the LCP ($n=19$, 57.6 %).

Only two patients were noted to be fully aware of their end-of-life diagnosis. Casenotes showed that end-of-life issues such as resuscitation and clinically-assisted nutrition were discussed with six patients, two whose care did not involve the LCP and four whose care subsequently did include the LCP.

Eighty families were aware that the death of their relative was a possibility. General plans for end-of-life care tended to be discussed with families whether patients were on the LCP or not, with no significant differences in rate between groups. In the LCP group, discussions were held with 54 (91.5%) families and in the non-LCP group with 26 (78.8%). For the 59 cases where care went on to include the LCP there was evidence that 48 (81.3%) of the families were involved in the decision.

4.14.7 Care relating to religious needs

Patients' religious traditions were better recorded in non-LCP casenotes ($n=24$, 72.7 %) than in LCP casenotes ($n=38$, 64.4 %) although the difference was not significant. However, LCP families were more likely ($p<0.001$) to have their spiritual needs assessed ($n=40$, 67.8 %) than non-LCP families ($n=5$, 15.2%). Religious needs were assessed for four patients, two in each group. Referrals to hospital chaplaincy teams were documented more frequently for patients on the LCP ($n=25$, 42.4%) than for patients who were not ($n=7$, 21.2%) although not statistically significant.

4.14.8 Care after death

Casenotes relating to sudden unexpected deaths ($n=8$) were included in this analysis. Death certificates were similarly frequently recorded as issued to LCP families ($n=30$, 50.8 %) and non-LCP families ($n=17$, 41.5%). The Scottish Government practical advice leaflet "What to do After a Bereavement" was recorded as issued significantly more frequently ($p<0.001$) to LCP families ($n=32$, 54.2%) than to non-LCP families ($n=4$, 9.8%). Similarly, booklets on coping with bereavement were recorded as issued significantly more frequently ($p<0.001$) to LCP families ($n=34$, 57.6 %) than non-LCP families ($n=4$, 9.8 %).

4.15 Answering the research questions

In respect of question 1, patients whose care was supported by the LCP appeared to be significantly older than those who died without the LCP. However, logistic regression analysis showed there were no significant predictive differences in terms of age, sex, stroke type (ischaemic or haemorrhagic), stroke severity or co-morbidity between groups in patients who died with or without the use of the LCP.

In relation to question 2a i.e. the clinical decision to use the LCP, clinical indicators such as stroke severity, clinical trajectory and sepsis were recorded by clinicians as indicators to use the LCP. Clinicians did not record age as a consideration in deciding to use the LCP. Patterns were noted in the timing of decisions to use the LCP. Decisions were most commonly recorded late morning and mid-to-late afternoon, and peaks in decisions were noted on Mondays and Fridays.

With regard to question 2b on experiences of LCP use, casenote data showed that the LCP was normally used for a short time, typically around two days per patient. However, in more than a third of cases, LCP use lasted more than three days and for a small group the LCP was used for more than a week. Similar proportions of casenotes in the LCP group and the non-LCP group showed evidence of agreed limits to treatment. Dysphagia, respiratory tract secretions and dyspnoea were the most commonly occurring symptoms in both LCP and non-LCP groups. Prescribing rates of several PRN medications to relieve end-of-life symptoms were significantly higher in LCP casenotes. Referrals to specialist palliative care services were rare (n=2).

Research question 3 could not be answered with casenote data because no patient on the LCP was discharged or transferred to another care setting during the casenote review period. However, the issue was explored in interviews and findings are reported in 5.27 and discussed in 6.3.5.

4.16 Key points for the discussion chapter

The key points identified from the casenote review were:

- No demographic or clinical factors were found to predict LCP use
- Weekday patterns were observed in decisions to commence the LCP
- The average duration of LCP use was less than three days but for a small number of patients, the LCP was used for one or more weeks
- Few referrals were made to specialist palliative care
- No patients on the LCP were discharged or transferred from the study sites.

The implications of the findings from the casenote review are discussed in Chapter Six, where findings from both study components are discussed and integrated. Before that, the conduct of the qualitative interviews and the related findings are reported in Chapter Five.

Chapter 5 – Interviews

5.1 Introduction

To begin this chapter, the aims, research questions and the research design for the qualitative study component are restated. Thereafter materials, methods and findings are presented. Sampling and recruitment are reported separately for bereaved relatives and for healthcare professionals. The researcher's preparation and training for data collection is reported. Additionally, the measures taken to limit the influence of the researcher's personal experiences are described. Thereafter the timing and generation of data with participants is addressed. Analytical methods are described before the characteristics of respondents and the data are reported and interview findings are presented. Throughout, extracts from the coding journal, memos and field notes are shown for illustration or to support statements made about the data. Coding journal extracts are shown in rounded rectangular text boxes, those from memos in grey text boxes and from field notes in dashed-edge text boxes. Finally, findings from the VOICES II survey administered in conjunction with semi-structured interviews are reported.

5.2 Aims of the interviews

- To examine experiences of end-of-life care pathway use for stroke patients, their relatives and the multi-disciplinary health care team
- To explore the clinical decision-making involved in placing patients on an end-of-life care pathway
- To explore the role of families in clinical decision-making
- To explore preferred place of care for patients on end-of-life care pathways in acute stroke units

5.3 Research questions

The qualitative component of the study was used to answer the second research question and sub-questions:

Question 2: What are family and health-care workers perceptions of using an end-of-life care pathway for patients who die after acute stroke?

Question 2a: How is the clinical decision made to place a stroke patient on an end-of-life care pathway?

Question 2b: What is the experience of end-of-life care pathway use for stroke patients, families and the multidisciplinary team?

Issues relating to the third research question i.e. discharge or transfer for end-of-life care in another care setting were also explored.

Materials and methods

5.4 Study sites and ethics approvals

As reported in 4.1, the study sites were four acute stroke units situated in one district general hospital and three city teaching hospitals across central Scotland. Data were collected in interviews conducted at the study sites, at the University of Glasgow and in participants' own homes.

NHS ethics committee approval was obtained for the qualitative interviews and questionnaire, as were honorary NHS contracts or letters of access, clinical governance and NHS Research & Development approvals (see 4.1.5.1). Delays to the approvals process are reported in **Error! Reference source not found..** The delays limited sampling in one study site and the issue is discussed in 5.7.3.2.

5.5 Sample: nature and size

Bereaved relatives of LCP patients, and healthcare professionals in the study sites were recruited for face-to-face semi-structured qualitative interviews. In order to maximise the scope for purposive and theoretical sampling, the researcher applied for ethics approval to recruit up to 60 bereaved relatives or healthcare professionals but with the caveat “or until data saturation.”

5.6 Sampling and recruiting bereaved relatives

The researcher aimed to recruit a demographically varied sample and to explore developing themes by sampling theoretically in the later stages of interview data collection.

5.6.1 Inclusion criteria

In line with the ethics approval, relatives were suitable for inclusion if they were next-of-kin, friend or carer for a stroke patient whose care involved the LCP in a study site. Relatives were included if they could speak English and were aged 18 or more. All relatives included in the study were *de facto* bereaved since, during the data collection period, all patients for whom the LCP was used died.

5.6.2 Exclusion criteria

There was concern from the academic supervisors that given the high incidence of stroke among elderly people, some elderly and frail relatives might be eligible to participate yet might have significant morbidity or impaired cognitive function. Consequently the ethics application stated that potential participants, who in the researcher’s clinical judgement should be excluded from the study, would be excluded. This exclusion criterion was never used.

5.6.3 Access and gatekeepers

Clinical staff acted as gatekeepers, identifying relatives who met the inclusion/exclusion criteria. The implications of having clinical staff as gatekeepers are discussed in 6.8.2. In each site after the LCP was implemented for a patient, clinicians (usually nurses) asked the patient’s relative for permission for the researcher to contact them in three to six months. If

no relatives were available key friends or carers were asked. If consent was given for contact, clinicians recorded the verbal consent on a proforma (Appendix 11) which was then placed in the casenotes and contact details were passed to the researcher.

5.6.4 Recruiting bereaved relatives

Three to six months later, the researcher and the patient's consultant signed a letter (Appendix 12) which the researcher sent to the relative, inviting them to participate in the study. A Participant Information Sheet (Appendix 13) about the study and a stamped addressed envelope were also included. Relatives could nominate another suitable person for interview if they wished. The researcher adopted methods reported in a Cochrane systematic review as effective in increasing responses to postal questionnaires (Edwards et al., 2009). These were: including a short personalised letter of invitation to take part, using coloured ink, sending by first class post and enclosing a stamped return envelope rather than franked and providing follow-up letters to non-respondents after two weeks. If relatives wished to participate, interviews were then arranged in venues of their choice. Relatives completed and returned consent forms (Appendix 14) to the researcher by post or completed consent forms with the researcher immediately prior to interview. Where consent forms were posted in advance, consent was confirmed immediately prior to interview.

As discussed in 3.12.2.3, elements of Sque, Walker and Long-Suthehall's (2014) framework were used to minimise potential distress associated with recruitment. These were:

- Staggering recruitment to avoid long waits for participants before interviews took place
- Recruiting at least three months post-bereavement
- Ensuring that covering letters of introduction addressed potential participants personally
- Allowing at least 10 days for bereaved participants to decide whether to join the study
- Avoiding interviews on significant dates such as decedents' birthdays.

- Repeat letters (Appendix 14) were sent after two weeks to non-respondents. Thereafter no further contact was made with non-respondents.

5.6.5 Purposive sampling with bereaved relatives

Efforts to select a purposive sample of relatives were hampered by the recruitment method. Relatives were recruited on an ongoing basis. Therefore it was only possible to identify where demographic variation was lacking later in the study. For example, it became clear that most relatives being identified, including those who did not respond to study invitations (see 5.18), were adult children of stroke patients.

To increase variation it would have been preferable to interview across a wider range of family relationships. Had it been possible to identify this issue earlier, gatekeepers might have been asked to approach relatives more selectively. Yet by the time the issue became apparent, time and funding constraints limited the researcher's ability to reject potential participants in case an insufficient sample was recruited. This limited some aspects of variation within the relatives' sample (see Table 5-6). Nevertheless the sample was reasonably varied by sex and socioeconomic grouping (see 5.18.1.1).

5.7 Sampling and recruiting healthcare professionals

A varied sample of healthcare professionals was sought from the four study sites.

5.7.1 Inclusion criteria

Members of specific healthcare professional disciplines working in study sites were eligible to participate. These were: registered nurses, health care assistants i.e. untrained nursing assistants, doctors of all grades from foundation years to consultant, speech and language therapists.

5.7.2 Exclusion criteria

Study grantholders, temporary staff i.e. agency, locum or bank staff and students were excluded. Physiotherapists, dieticians and occupational therapists were not included because fieldwork (see 3.9.5.2) indicated that these disciplines were not commonly included in end-of-life decision-making or care.

5.7.3 Recruiting healthcare professionals

Senior charge nurses identified potential participants to the researcher when she was visiting study sites to collect casenote review data. Doctors, registered nurses, healthcare assistants and speech and language therapists working in study sites were then sent a letter of invitation (Appendix 15) with a tailored Participant Information Sheet about the study (Appendix 16), a consent form (Appendix 17) and a stamped addressed envelope. Letters were sent care of senior charge nurses, therapy departments or via medical secretaries. Inclusion in the study was not linked to caring for the deceased patients whose notes were reviewed (see Chapter Four). Repeat letters (Appendix 15) were sent after 2 weeks to non-respondents who met purposive requirements. Potential participants responded to invitation letters either personally when the researcher was collecting casenote review data in their stroke unit, or by phone or email or by returning the completed consent form. Interviews were then arranged in the participants' venues of choice.

5.7.3.1 Delays to healthcare professional recruitment – Site D

In site D the local LCP co-ordinator planned to administer a questionnaire examining staff attitudes to the LCP. This would take place during the early stages of data collection for the study reported here. Therefore it was agreed to delay recruiting healthcare professionals at study site D for three months until the staff attitudes survey was complete, in order to minimise participation fatigue.

5.7.3.2 Purposive sampling with healthcare professionals

Initially the researcher intended to recruit purposively from all sites concurrently. However, experience of recruiting healthcare professionals for interview in a previous study (Cowey et al. 2012) indicated that response rates from healthcare professionals might be low. Therefore invitations were issued to all relevant staff simultaneously in each site and respondents were then purposively sampled, in order to obtain a maximum variation sample within a realistic timeframe. Delays in approvals (see 4.1.5) and to accommodate local research (see 5.7.3.1) meant that data collection was staggered and began later in Site D than in other sites. Consequently, more participants were recruited from sites A to C and

by the time recruitment could begin in site D, data saturation was approaching. Therefore fewer healthcare professionals and relatives were recruited at site D.

Senior charge nurses stated healthcare assistants and speech and language therapists (SALTs) had limited involvement in end-of-life decision-making, and this was confirmed in early interviews. Therefore these disciplines were invited in three sites (A to C) only. Large numbers of healthcare assistants (n=47) were employed across the sites so the researcher used charge nurses' recommendations to invite only healthcare assistants with an interest in end-of-life care. In the case of SALTs, only one therapist worked in each stroke unit hence all SALTs from Sites A-C were invited to participate. The deliberately narrow purposive sampling of healthcare assistants and SALTs was confirmed by the limited involvement in decision-making which they described in interviews. Additionally, while SALTs reported useful data on feeding issues, they had limited knowledge of LCP-related decision-making or of the impact of the LCP in their stroke units.

Accordingly, after two interviews with healthcare assistants and three with SALTs it was decided to not to seek further interviews. Middle grade and senior doctors were reported by participants to be central to decision making and so recruitment was focused accordingly. Seven potential participants who consented to take part were not included in early interviews; these individuals gave permission for the researcher to return to them purposively later in the study if further interviewing was needed to confirm or explore emerging themes. This was not required. Thus a maximum variation sample was recruited from all the healthcare professional respondents.

5.8 Theoretical sampling

According to Charmaz (2000) the aim of theoretical sampling is to recruit participants whose reports are likely to enrich the researcher's understanding of the emerging categories, thereby informing the developing theory. Thus theoretical sampling is theory-driven, and is distinct from purposive sampling which aims simply to sample a wide variety of people with a common experience (Charmaz, 2000). The researcher aimed to sample theoretically but some barriers were encountered.

First, the limits to purposive sampling with relatives (see 5.6.5) also affected the potential for theoretical sampling in that group. Relatives were identified by clinical staff for study inclusion three months before they could be contacted by the researcher. Consequently by the time themes were developing, if the researcher wanted to specify particular types of relatives to recruit she would have to wait three months for suitable participants. Because the themes emerged in the later stages of the study there was little time or funding scope for this. In practice, the researcher had to choose from the existing recruitment pool. All willing family participants had to be included in case an insufficient sample was recruited.

Second, the researcher did not have ethics or governance permissions to recruit in clinical areas beyond the acute stroke units. This governance limitation affected theoretical sampling for the emerging theme of “Prolonged Dying” in the following way. The theme reflected the heightened distress of families and staff when patients took longer than expected to die. Yet several clinicians reported at interview that some patients with severe stroke died quickly in medical receiving units before transfer to the study stroke units, and that these patients might be cared for using the LCP. Therefore it would have been helpful to sample relatives and staff involved with such patients because they might provide negative case data (i.e. reporting experiences of rapid dying) for the “Prolonged dying” theme. No such families were recruited in the study stroke units. Consequently theoretical sampling for that theme was limited.

5.9 Supporting the recruitment strategy

Courtesy emails were sent to stakeholders i.e. consultants, managers and senior nurses in stroke and in palliative care in all sites to notify them of the study’s commencement. In the early weeks of the study, clinical staff reported to the researcher that they did not approach three families who were potential participants. Thus it became apparent that although senior charge nurses were well-briefed and supportive, the necessary information was not being cascaded to all staff and opportunities for gaining consent for contact were being missed. Accordingly, the researcher reworded the verbal ‘consent for contact’ form (Appendix 18) to maximise clarity and developed an A4 staff information poster for display in duty rooms (Appendix 19). Both alterations were approved by the NHS ethics

committee as minor amendments (Appendix 20) and copied to NHS Research & Development departments via NHS Research Scotland Permissions Co-ordinating Centre.

The researcher also discussed suitable strategies for raising awareness about the study with senior charge nurses in the study sites. In sites C and D, the senior charge nurses asked the researcher to hold short briefing sessions about the study with ward nursing staff. The sessions lasted ten to 15 minutes and included opportunity for staff to ask questions and discuss the study. In all sites, senior charge nurses displayed the information poster in duty rooms. Further, in each site the researcher left a study resource folder containing contact details for herself and the site Principal Investigator, additional verbal consent forms and a copy of the information poster. The researcher also chatted informally to staff about the study while collecting casenote review data at study sites.

5.9.1 Presence of the researcher as a factor in recruitment

The researcher visited each site once or twice a week to collect casenote data, usually working at the nurses' station or in doctors' offices where she often interacted with the nursing, medical and AHP staff or visitors to the stroke units. As a result of this interaction staff appeared to become comfortable with the study and seemed increasingly willing to ask relatives for permission to contact. Some staff also spontaneously expressed willingness to be interviewed.

5.10 Data collection tools

5.10.1 Developing the interview guides

Tailored interview guides were developed for both interview groups to elicit experiences of decision-making and using the LCP. The guides were designed to explore the research question from the distinct perspectives of each group. Therefore the interview guide for relatives focused on experiences of LCP-based care and inclusion in decision-making whereas the guide for healthcare professional interviews focused on process aspects of decision-making.

Using Charmaz (2001) and Ziebland's (2013) approach, an open initial question was used. This acted as an icebreaker and also allowed participants to give their own narrative

uninterrupted. Thereafter the interview guides incorporated several more focused questions that allowed the researcher to probe particular issues if participants had not already covered those fully, or prompted the researcher to ask about issues not spontaneously mentioned. Both schedules concluded with a catch-all item asking participants to identify any issues not already covered. The interview guides were drafted and then pilot work was undertaken.

5.10.2 Piloting

Pilot interviews were conducted to establish the clarity and acceptability of the wording, to check that the order of questions made sense to participants, to ascertain likely interview duration and to test the recording equipment. Both interview guides were piloted with colleagues who were postgraduate nurses studying for a PhD or working in higher education and who had personal and professional experience of end-of-life care (n=2). Following testing, minor adjustments were made to the interview guides. Several items were rephrased for clarity and the questions were re-ordered. The initial interview guides for each group are shown in Appendix 21 and Appendix 22. Prompts for the interviewer to use as probes, if required, are shown in italics.

5.10.3 VOICES II survey tool

The VOICES II interview tool was pre-validated and reported to be acceptable for use with bereaved relatives (Young et al., 2009). Nevertheless it was included in the pilot interviews to check how well it fitted with the interview guide. The pilot interviews confirmed that it suited the interview flow to administer the VOICES II tool after the main semi-structured interview. This was useful for identifying items that had not been addressed and helped the interviewer to signal the end of the interview to participants, identified by Kvale (1996) as good interviewing practice. The final guide for interviews with relatives is shown in Appendix 23.

5.10.4 Iterative modifications to healthcare professional interview schedule

In keeping with the grounded theory approach to data collection, new items (n=2) were added to the healthcare professional interview schedule as data collection progressed, in order to explore emerging issues. First, some interviewees indicated that where the LCP paperwork could not be completed and the tool used formally - for instance if a patient deteriorated rapidly - staff might still use guidance contained in the LCP documentation to

provide end-of-life care. For example staff reported anticipatory prescribing could be used even if the LCP was not commenced. Accordingly, a question on the issue was added to the schedule.

Second, some healthcare professionals reported that decision-making varied at weekends, either with decisions to use the LCP being more common on Fridays in advance of the weekend, or being delayed until the following Monday. An exploratory question was therefore added to the interview schedule and a post hoc analysis of casenote data was undertaken (see 4.13.3.2). The final guide for interviews with healthcare professionals is shown in Appendix 24.

5.11 Preparing for data collection

Before the qualitative data collection began, the researcher addressed her own training and knowledge needs. Despite previous experience in qualitative interviewing (Cowey et al., 2012), the researcher required training in conducting sensitive interviews and consequently undertook a one-week qualitative research methods training course with the Health Experiences Research Group (University of Oxford, 2015). The course included sessions on conducting upsetting or difficult interviews. Additionally, the researcher attended a study day on bereavement run by the local health authority. Finally, in preparation for interviewing the researcher considered the work of Bonanno et al. (2002) and Bonanno (2009) which challenged widely accepted concepts of bereavement as a linear process (Kübler-Ross, 1970). Bonanno and colleagues emphasised the emotional resilience demonstrated by bereaved individuals in several of their observational studies of bereavement in the US. This reading supplemented feedback (see 3.12.2) from bereavement researchers around the UK who advised that interviewing three to six months post-bereavement was generally acceptable to UK participants and that some found participation beneficial. Consequently the researcher felt adequately prepared to undertake potentially upsetting interviews with recently bereaved people.

5.12 Supporting the researcher

Lone working in participants' homes was deemed a potential risk for the researcher. The university policy (University of Glasgow, 2010) on lone working was followed. Therefore the researcher carried a mobile phone when interviewing and left details with a university administrator of the address being visited. The researcher phoned the administrator on arriving at and departing from the interview venue. Emotional support and debriefing for the researcher was provided by the primary academic supervisor.

5.13 Data collection: timing

Interview data were collected between February 2012 and January 2013. Interviews with healthcare professionals began first (Feb 2012) but were timed to last throughout the period when relatives were also interviewed (beginning May 2012). This allowed emerging themes to be explored and developed with both groups.

5.13.1 Timing of contact with relatives in Site D

The researcher aimed to interview within a period of three to six months post-bereavement (see 5.6.4). However, in site D, the charge nurse routinely undertook bereavement follow-up with relatives by letter at three months post-bereavement. It was therefore agreed that to avoid confusion or overlap the researcher would delay sending letters of invitation until four months post-bereavement or later, as advised by the clinical team. There was no routine bereavement follow up at other sites.

5.14 Presence of the researcher on stroke units as a factor in data collection and analysis

The researcher's presence for casenote data collection in the study sites appeared to increase staff interest in study recruitment (5.9.1). It also triggered spontaneous conversations between the researcher and the staff that enriched the qualitative data collection and analysis.

Some developing themes were confirmed or different aspects for exploration were suggested. For example, two months into casenote data collection in site D the researcher spent a morning working on casenotes in an office used by several nursing staff and junior doctors. Intermittently the senior charge nurse, who was also working in the office, initiated and led two conversations with the researcher and healthcare professionals passing through the office about using the LCP. The researcher made it clear to those involved that the conversations were not being recorded but wrote field notes. The field notes augmented the analysis of interview data from other sites, confirming issues emerging from interviews and coding at Site B. First, Site D staff echoed the reports of Site B staff that if there were barriers to LCP use, they might use LCP principles of care without the formal documentation (5.10.4). It was unclear whether this approach was the flexible use alluded to in the Scottish Government (2008) document (see 2.8.2) and the issue is discussed further in 6.3.3. Second, the Site D staff reported a stepped decision-making process leading to LCP use and this accorded with the “Deciding is ‘a series of crucial steps’” theme (see 5.24) emerging at other sites.

5.15 Interviews

5.15.1 All interviews: Informed consent

Written informed consent was obtained prior to interviews. If participants had returned completed consent forms by post, the researcher reviewed the consent with participants immediately prior to the interview, inviting questions and checking the participant understood the study and still wished to be interviewed. Before interviews began the researcher also reminded participants that they could take breaks or stop the interview at any point without giving a reason. All interviews were recorded using a small portable digital voice recorder.

5.15.2 Interviews with bereaved relatives

Semistructured interviews lasting 30-45 minutes were conducted using the interview guide to elicit experiences of decision-making and the impact of LCP use. Thereafter, quantitative data were collected via the VOICES II tool (see 5.15.2.2). Interviews were

conducted in locations selected by participants, commonly their own homes. The semi-structured interviews typically lasted around 30-45 minutes.

5.15.2.1 Presence of others

Spouses or family members spontaneously joined some interviews for a few minutes or greeted the researcher briefly and left. The researcher did not seek informed consent from these others for their brief interaction and hence did not transcribe their words. Where these family members contributed to the interview discussion their input generally supported participants' accounts and yielded no new information.

In one case when the researcher arrived to conduct an interview, a husband indicated his intention to join his wife's interview. The researcher established that his wife wished a joint interview and that he had read the Participant Information Sheet sent to his wife, answered his questions and obtained written informed consent for his participation. He then became a participant in the study.

5.15.2.2 Data collection with VOICES II survey tool

At the end of the semistructured interviews with relatives, the stroke-specific version of the Views of Informal Carers' Evaluation of Services (VOICES) tool (Young, Rogers and Addington-Hall, 2008) was administered face-to-face. The authors gave permission for use (see Appendix 25). Completing the VOICES II survey took ten to 15 minutes. The researcher read the questions and response options to participants and recorded their responses on paper forms using anonymised case identifiers. Thus the VOICES II questionnaire was administered as a structured component of the interview, rather than being self-administered. The rationale for this approach was that this method was used in the tool's original development and validation (Addington-Hall and McCarthy, 1995; Addington-Hall et al., 1998).

5.15.3 Interviews with healthcare professionals

Participants chose to be interviewed in quiet rooms in the participating stroke units or in hospital offices. Semistructured interviews typically lasted 25–40 minutes. The interview

guide was used to elicit experiences of recognising dying, implementing the LCP and wider end-of-life care issues.

5.15.4 Supporting participants

The researcher adopted a protocol for minimising or handling distress in participants (see 3.12.2.2). These were:

- For bereaved relatives, offering the possibility of having a friend or family member present at interview
- Emphasising at the outset that the interview was voluntary and participants might withdraw at any time
- If the participant became distressed during interview, offering to take a break or stop the interview altogether
- Actively listening to individuals' concerns. Providing telephone numbers of voluntary organisations, such as CRUSE and The Samaritans, when appropriate.

5.15.5 Field notes

The researcher made field notes in the hours immediately after each interview. Field notes were used to record salient features of interviews as an aide memoire for the researcher. These could include gestures, interruptions, comments made on arrival or departure i.e. when the voice recorder was switched off and noting if colleagues or family members joined interviews. Field notes were also used to record emerging issues, and occasionally links the researcher noticed with other interviews, as recommended by Holloway and Wheeler (2010). Box 5-1 shows a sample extract from an interview field note, recording the circumstances of the interview, the researcher's impression of the participant's attitude and the comparison drawn with another participant. Using field notes in this way stimulated the researcher to think not only about comparisons within the data but also about similarities and differences among participants. Hence making comparisons between

interviews in this field note helped to identify common characteristics of negative cases in the theme “Care quality” (see 5.22).

Box 5-1 Extract from field note on the interview with Relative 7

Field note: interview with Relative 7

Young mum, two small children in another room during interview. Practising nurse.* We were both in our bare feet (wet summer day, immaculate house – left shoes at door). She seemed a bit angry, actually. I began to think this about 15 minutes into the interview. She spoke fast and had lots to say (critical) about the stroke unit.

*Second critical nurse – is this relevant?

5.15.6 Post-interview contact with participants

Between one and three days after interview, a photocopy of the consent form was posted to participants, with a handwritten note of thanks on the accompanying compliment slip.

5.16 Data storage

Data were handled and stored in line with the 1998 Data Protection Act (Legislation.gov.uk, 2015), with the NHS Confidentiality Code of Practice (NHS Scotland, 2003) and University of Glasgow guidance (University of Glasgow, 2015). These stipulate that data should be stored securely in an anonymised form and that data should be stored only for as long as needed. Accordingly, interview consent forms (paper) were stored securely at the university. Interview voice files and transcripts were stored electronically on a secure university server, using anonymised study numbers as identifiers. The server files were password-protected and accessible only by the researcher. Interview voice files were destroyed, after transcription, within three months of the data collection period ending. The ethics committee approval allowed the researcher to retain consent forms and transcripts until successful completion of the project, to enable reporting of results, including publication in peer reviewed journals, and completion of the researcher's PhD.

5.17 Coding and analysis

5.17.1 Underpinning approach

Coding and analysis were undertaken using principles of modified grounded theory development described by Hutchison, Johnston and Breckon (2010). These included an iterative process of data collection and analysis, the use of analytical codes and categories arising from the data and the use of systematic comparisons to identify patterns in the data. Specifically, hierarchical coding methods identified by Charmaz (2006) as consistent with a modified grounded theory approach were adopted (see 3.10.1). These were:

- Initial detailed line-by-line coding, a method that enabled the researcher to avoid making early assumptions about the data
- Use of participants' own words as coding labels where possible
- A focused coding stage, where line-by-line coding was rationalised into categories
- An axial coding stage where categories were grouped into themes. Data coded to themes were then scrutinised in depth.

Further, Charmaz (2006) accepts that developing theory is constructed jointly by researchers and participants. Charmaz (2006) therefore emphasises the need for researchers to maintain awareness of their own influence on data generation and analysis. Accordingly, the researcher sought to reflect on her influence on data by using memos and field notes, and by creating an auditable record of data collection and coding decisions.

5.17.2 Transcription

The researcher transcribed all the interviews verbatim, as recommended by Bazeley and Jackson (2013). Events such as laughter, tears, interruptions to interviews and short or long pauses were indicated in italicised square brackets within the transcript text. Transcription was normally carried out within 48 hours to minimise loss of recall.

The fact that the researcher undertook the transcription enhanced opportunities for analysis. For example, considering how to punctuate particular sections accurately often

pushed the researcher to analyse more closely what participants had said. Additionally, during transcription the researcher was mentally immersed in the data and could clearly identify some similarities and differences with previous transcripts, thereby feeding a process of constant comparison as described by Miles and Huberman (1994).

5.17.3 Reading and field notes

The researcher read through the transcripts and made initial notes on key issues. Field notes for each interview were read with the relevant transcript and used for context. For example, field notes were used to remember *how* things were said that were not captured in transcripts e.g. gestures, whether participants seemed angry or withdrawn and comments made when the voice recorder was not switched on. Any additions to transcripts were then made. Completed transcripts were imported into NVivo 9 (QSR International Ltd, 2010) which was used to organise the thematic analysis.

5.17.4 Initial coding

Initial line-by-line coding as described by Charmaz (2006) was performed on the transcribed interviews. Codes, or labels using a few words, were used to summarise sentences or phrases that expressed similar concepts. As far as possible, initial codes used the *gerund* (verb acting as noun) as expressed by participants. Gerunds are identified by Charmaz (2006) as useful for capturing participants' actions, rather than using passive labels for topics that generate a descriptive list of categories. For example, the quote, "...I normally go through a kind of general discussion about the natural history of stroke..." (Doctor 1) was coded as 'Going through facts', rather than 'Type of information given'. Charmaz argues that by using gerunds, one stays closer to the data and to the participant's view and avoids making assumptions too early about the nature of the data. Additionally, where possible, codes and themes were labelled using *in vivo* codes (Creswell 2007) i.e. using the participants own words as labels. Again, this helped to stay close to the data and avoided imposing the researcher's view. Table 5-1 shows an example of initial coding.

Table 5-1 Section of transcript showing examples of initial line-by-line coding and in vivo codes (shown in italics)

Transcript excerpt	Coding label
<p>"I did a few overnights with him...and there was a few things that I didn't like that I'd mentioned to a few of my friends who were also nurses... A couple of times I'd said, 'Could I get him some morphine?' And ... she went, 'Well, wait a minute, I'm just a bit busy. I'll come back to you.' And that got to me cause I thought 'No, no. I'm a nurse and I wouldn't do that to any patient.' And also other friends were, 'Oh yeah, you wouldn't do that.' So... I heard from the girl across the road, who is also in research, she's a speech and language therapist researcher, and she was saying... the stroke unit at [names Site C] were having real issues, so the girl across the road was saying. I was over for a coffee and she said, 'No, I've been up,' – cause she obviously goes up and does research – 'He was TUPed in from [names another hospital].'" (Relative 7)</p>	Doing overnights
	Discussing with friends
	Asking for care
	Being asked to wait
	Comparing with self
	Confirming with friends
	Hearing from neighbour
	<i>I was over for a coffee</i>
	Getting inside information on stroke unit

Inductive codes i.e. those emerging from the data as illustrated in Table 5-1 were generated first. Thereafter the researcher cross checked with field notes and the interview transcript to see if any additional *a priori* or 'pre-figured' codes (Creswell 2007) were required. Transcripts were constantly compared to find similarities or differences in coding. Interview transcripts from relatives and healthcare professionals were entered into NVivo and coded separately. During analysis, both group-specific and shared themes emerged and these are reported in later sections.

Although data were stored in NVivo from the outset, initial line-by-line coding was performed on paper for the first seven transcripts from relatives' interviews and eight from healthcare professional interviews. Thereafter, focused coding was established electronically in NVivo. This strategy helped to reduce the number of codes to be created in NVivo, as there were more than 150 line-by-line codes. Thus coding began in NVivo during the focused coding stage which is reported next.

5.17.5 Focused coding

In the focused coding stage (Charmaz, 2006), early line-by-line codes were rationalised and condensed into categories. Thus in the example shown in Table 5-2, text describing how relatives used their established social networks to glean information were grouped

into the category 'I was over for a coffee' since this *in vivo* code summarised the concept of informal networking in a participant's own words. Similarly, labels that described incidents of good or poor care and participant's responses to care were grouped into the category of 'Care being good or not'. Focused coding was performed on all interview transcripts, initially working from line-by-line coding on paper transcripts and later in the project working directly on transcripts stored in NVivo. As described by Charmaz (2006) the focused coding stage was not completely a linear process; ongoing data collection and constant comparison of data triggered the researcher to review previous transcripts, establishing additional codes and categories iteratively. The researcher either re-read previous transcripts or used the search function in NVivo to find specific terms. In all, 103 focused coding categories were established.

Table 5-2 Example excerpt from interview transcript showing how initial line-by-line coding labels were condensed into categories

Transcript excerpt	Coding label	Category
<p>"I did a few overnights with him...and there was a few things that I didn't like that I'd mentioned to a few of my friends who were also nurses... A couple of times I'd said, 'Could I get him some morphine?' And ... she went, 'Well, wait a minute, I'm just a bit busy. I'll come back to you.' And that got to me cause I thought 'No, no. I'm a nurse and I wouldn't do that to any patient.' And also other friends were, 'Oh yeah, you wouldn't do that.' So... I heard from the girl across the road, who is also in research, she's a speech and language therapist researcher, and she was saying... the stroke unit at [names Site C] were having real issues, so the girl across the road was saying. I was over for a coffee and she said, 'No, I've been up,' – cause she obviously goes up and does research – 'He was TUPEd in from [names another hospital].'" (Relative 7)</p>	Doing overnights	Work of visiting
	Discussing with friends	<i>I was over for a coffee</i>
	Asking for care	Asking for care
	<i>Wait a minute</i>	Care being good or not
	Comparing with self	
	Confirming with friends	
	Hearing from neighbour	<i>I was over for a coffee</i>
	<i>I was over for a coffee</i>	
	Getting inside information on stroke unit	

5.17.6 Second reviewer and coding

Coding for the first ten transcripts (five from healthcare professionals and five from relatives) was reviewed by the first academic supervisor who agreed the labels and condensed categories. In addition, the coding reviewer noted how frequently senior doctors reported moving around the hospital, sometimes making only brief visits to stroke units, and their consequent dependence on the wider team for information about patients. Therefore at the reviewer's suggestion, a code of 'Geography' was used to capture this action of clinicians. The Geography code was later re-grouped into the 'Proactive information-giving' theme because it emerged as part of a wider issue where the geographical movement of healthcare professionals proactively towards families was

important in perceived support (see 5.26). The development of themes is now addressed in detail.

5.17.7 Axial coding

Step 1: Identifying themes

After categories had been established through focused coding, a process of axial coding (Charmaz, 2006) was performed, where similar categories were combined to eliminate duplication. This reduced the total to 66 categories. Links between categories were then examined, and related categories grouped together to form themes. Table 5-3 illustrates how text sections were coded to categories and how categories were grouped into themes. The final number and names of themes, as well as their content, is reported in 5.20.

Table 5-3 Example of data coded under a theme, showing how focused coding categories were grouped into themes

Transcript excerpt	Focused coding category	Theme
"A couple of times I'd said, 'Could I get him some morphine?'" (Relative 7)	Asking for care	Active families
"... I was cleaning her mouth myself, doing all sorts of things like that..." (Relative 1)	Giving care	
"I got the priest to come up and give my mother the Last Rites." (Relative 3)	Organising religious care	
"... if I expressed the opinion that my mother was in pain or if [names wife] did, you'd know that they would... give some pain relief... almost as if we were making the decisions." (Relative 14)	Being involved in decisions	
"...I heard from the girl across the road... The stroke unit at [names Site C] were having real issues, so the girl across the road was saying. I was over for a coffee and she said..." (Relative 7)	<i>I was over for a coffee</i>	
"... I had to go and ask questions but that was for me to explain to the rest of the family. Because I'm aware that if four different people are going to visit my dad and every one of them wants to know then yes, the doctor can come and speak to you but however my brother was in [names another town], my sisters were visiting different times. I said, "I will be the person who goes and asks." (Relative 5)	Negotiating with other family members	
"So I kept questioning, kept asking and they just couldn't give me answers." (Relative 4)	Seeking information	
"She just had that look... we'd seen a few people come and go...you could see and hear them, their breathing changing... so I was becoming more knowledgeable." (Relative 16)	Working out by observation	
"...wouldn't have been a pushy family. A lot of folk go in expecting, demanding. And I was like 'You wouldn't do that because you want the best, you want them to look after your loved one. So why would you want them to be on the bad side of you?'" (Relative 8)	'Getting on the good' side of staff	

Charmaz (2006) did not explicitly use the term ‘theme’ in reporting her analytical method, nevertheless the researcher used the term for this study because it fitted the analysis and with other literature. In this analysis, the term ‘theme’ was used in the sense given by Richards (2015) i.e. that a theme is an integrative concept emerging from the data, bringing together several ideas or aspects of an issue, rather than simply a superficial list of topics covered. Bazeley (2009) recommended that themes are used as a starting point before analysis is deepened and this final analytical step is now described.

Step 2: Exploring themes to deepen the analysis

Ziebland and McPherson's (2006) One Sheet of Paper (OSOP) method was used to explore the themes identified in the data. For each theme, an NVivo coding report was printed out. The report contained all interview data coded to the theme. The researcher read through the data and on a large single sheet of paper briefly noted each issue raised, along with the relevant respondent's anonymised ID. Similar issues were grouped together in a mind-map structure (see Appendix 26). Thus the complete OSOP yielded an inter-related summary of all issues contained within a theme, showed the range of respondents and views including negative and infrequent cases and allowed identification of some relationships between issues. For example the linear decision-making process within the theme ‘Deciding is “a series of crucial steps”’ became apparent (see 5.24).

Where an OSOP demonstrated contrasting views on an issue, a matrix was used to explore the variations, as recommended by Bazeley (2009) and Wyke et al. (2010). According to Wyke et al. (2010) matrices can be used to pull out and organise data on specific aspects of individual transcripts. Text data is included in the matrix as evidence to support statements being made about the data. Extracts from many transcripts may then be grouped to build understanding of similarities or differences within themes. For example, in the theme entitled ‘Prolonged dying’, a matrix was used to explore whether LCP duration and relatives’ beliefs about the duration of the dying process might be associated with reports of distress (see Table 5-4). Additional matrices were then used to explore factors that might mitigate distress and this is reported in 5.25.

Table 5-4 Extract from matrix showing examples of relatives' reports of duration of dying process and related reports of discomfort with that duration of dying

Study ID	LCP duration	Did relative believe dying was prolonged?	Did relative report dying process was distressing?
Relative 17	5 days	No “... They just stopped feeding her and things, and then five days later she passed away, so it was only really five days that we knew she was dying.”	No “Just glad she never suffered; that's one thing that we were thankful of - that she never suffered. She didn't ever seem in a lot of pain; she was kept comfortable.”
Relatives 2 and 3	2 weeks	Yes “Over the course of three weeks – it took my mother three weeks to pass away.”	Yes “I just wish it would have happened sooner rather than the three weeks. Because to me it was just murder to watch my mother lying there, not being able to do anything. Can't eat, can't drink.”

Step 3: Identifying subthemes and overarching themes

During the axial coding stage, subthemes were identified, in addition to full themes. Subthemes were key issues within a theme that were sufficiently distinct almost to stand alone but were so relevant to the main theme that the researcher classified them as related in a key way. For example, recognising dying and negotiating subsequent care were distinct issues on which participants expressed a range of opinions, yet both were integral to the decision-making process and so were treated as subthemes. Additionally, according to Braun and Clarke (2013), an ‘overarching theme’ incorporates a concept that runs through several themes. Overarching themes were identified and are reported in more detail later (see 5.21, 5.22).

5.17.8 Organising categories and themes using NVivo

The software package NVivo was used to organise and store the qualitative data using the following steps:

Stage 1: All electronic interview transcripts were imported into NVivo.

Stage 2: Focused coding was initially established on paper for the first fifteen transcripts and thereafter the researcher recreated the paper codes electronically using NVivo to categorise the stored transcript data. In NVivo, text data is selected using the highlight function and saved to a coding node, or file (Bazeley and Jackson, 2013). Nodes may be free-standing (free nodes) or linked through a hierarchical structure known as tree or parent nodes, and child nodes. The researcher created tree nodes for all focused coding categories, then highlighted and saved each section of transcript text labelled with a focused code to the corresponding NVivo tree node. Categories which after focused coding were not obviously related to any others were coded as free nodes and moved into the tree structure if necessary during later coding. Examples of free nodes are shown in Box 5-2. At the end of data analysis, four free nodes remained which contained relevant background information but had not been coded into the major themes. These were retained and used to provide a thick description of the study context and are presented in 5.19.2.

Box 5-2 Screenshot showing examples of free nodes created during the coding process. (Screenshot shows coding status towards end of data analysis period but before completion).

Free Nodes				
Name	Sources	References	Created On	
Not rushing the process	2	2	26/06/2012 12:57	
Not using the LCP for dying patients	2	4	20/03/2012 11:32	
Notion of end of life care in stroke	6	7	31/07/2012 12:32	
Possible theme of effective LCP official LCP	0	0	12/03/2012 13:50	
Possible theme of preferred place of care	0	0	12/03/2012 13:48	
Possible theme of recognising dying in stroke	0	0	12/03/2012 14:55	
Reflecting on practice	3	5	25/03/2013 09:22	
Thrombolysis	4	7	26/03/2013 11:57	
USEFUL QUOTES	10	17	06/02/2013 11:20	
Yes, LCP is pathway in use	7	7	20/03/2012 10:47	

Stage 3: Thereafter all coding was carried out electronically via NVivo and progressed in step with data collection. During axial coding, tree nodes for related categories were dragged and dropped together, creating child nodes under a parent tree node. Nodes were rearranged and renamed as required according to the developing analysis. Thus tree nodes were established for the major themes and child nodes for a hierarchy of subthemes and subcategories. Box 5-3 shows an example of a tree node for the theme named ‘Active families’ with its related child nodes.

Box 5-3 Screenshot showing the developing tree node and related child nodes for the 'Active families' theme

Tree Nodes			
Name	Sources	References	Created On
Active families	39	411	15/04/2013 14:48
Asking for care	18	37	05/02/2013 09:56
Giving care	7	15	05/02/2013 12:36
Organising religious care	11	19	05/02/2013 09:55
Being involved in decisions	21	38	08/03/2012 14:19
'I was over for a coffee'	10	20	10/10/2012 09:41
Negotiating with other family members	14	32	05/02/2013 13:44
Seeking information	13	41	05/02/2013 14:24
'Working out by observation'	9	14	08/04/2013 12:59
'Getting on the good side' of staff	4	8	27/03/2013 10:43

5.17.9 Coding journal

In this study the researcher used a coding journal to establish an audit trail of coding decisions, thereby enhancing dependability. A coding journal is described by Clarke (2011) as a way to record evolving analysis. For example, the extract in Box 5-4 recorded the creation of a new category that triggered the researcher to search previous transcripts for evidence of similar data (including negative cases). The extract also documents the search methods used. This category was eventually developed into the theme entitled “Wondering about home or hospice care” (see 5.27). Thus the coding journal provided a record of data handling, data interrogation and coding decisions, establishing a record of how categories and themes were developed.

Box 5-4 Example of a coding journal entry recording the creation of a new coding category

08/04/2013 10:46

Entering focused coding for Relative 12 and created new tree node of 'Thinking about things after' - relatives having questions after the care episode. Added another couple of relatives to this category after comparison across transcripts (searched in MS Word with 'question', 'wonder' and 'thought').

5.17.10 Using memos

According to Holloway and Wheeler (2010) memos are used both to record the developing qualitative analysis and are also part of that analysis, being themselves inherently analytic. Memos are records of the researcher's rationale for organising the data in the chosen categories or themes, and show how these were developed through the researcher's questions or links made with other themes or comparisons with literature. In other words memos could be described as field notes about data analysis. In this study, memos were established in NVivo for focused coding categories and subsequently for themes. These summarised the content and origin of nodes and specified what data were included and excluded. This guided the researcher with future coding.

Further, the researcher expanded the memos over time, recording how and why nodes might be merged, or considering links within and between nodes. For example Box 5-5 shows an extract from the coding memo on the theme of "Prolonged dying" (see 5.25). The extract shows what content was coded to the theme, recording that the theme began as a child node of another concept and was upgraded to an independent tree node. The extract also shows how the researcher's act of transcribing triggered her to interrogate the node contents further, identifying another key category on expectations which later became the subtheme "Managing expectations" (5.25). Additionally, writing the memo stimulated the researcher to reflect on possible recruitment bias as well as identifying the potential contextual use of quantitative data. Thus using coding memos augmented the analytical audit trail, stimulated analysis and encouraged the researcher's methodological reflexivity.

Box 5-5: Extract from coding memo on the theme “Prolonged dying”

Node properties

This node includes data on the duration of the dying process i.e. the duration of LCP use and/or the time period when staff or family believe a patient is dying but LCP is not yet begun. It also includes clinician and family views, both positive and negative, on the duration of dying. This node also includes the content of clinicians’ communications on expected duration of dying. However the manner in which information was given is excluded and should be coded instead to “Pro-active information-giving”.

Memo content (sample extract)

27/03/2012 13:19

'Coping with prolonged dying' created as part of 'It's difficult' (difficult to use formal LCP in situations where patients go through long decline).

08/10/2012 11:44

'Prolonged dying' - usually discomfort or surprise expressed about this by relatives and healthcare professionals. Created as a separate focused node

22/01/2013 08:38

Transcribing Relative 16. Again, discomfort with prolonged dying. "We weren't expecting it to be as long." Key questions: What shaped their expectations? How well are the healthcare professionals preparing families for the possibility of a prolonged dying process? This (expectation) is a definite category - will it be a theme or will it be part of a larger theme?

A thought - check how many relatives discussed prolonged dying. I think it was quite a few - did this influence recruitment? Was it easier for staff to ask families to take part if they were around the ASU for a while? What does this say about the sample? Also cross check with length of time on LCP from audit.

Note Relatives 16 and 17 picked up cues from the ward about dying, without being told - from observing other patients, ward routines or just listening? 8/02/13 - *This could help to shape their expectations - do both belong to a theme of “Expectations”?*

Memos were also used to minimise the influence of the researcher’s personal experience on the analysis. During the data collection and analysis period, the researcher experienced three close personal bereavements, one of which was caused by stroke. In line with recommendations from the literature (Reeves, Kuper and Hodges, 2008; Maxwell, 2008) memos were used to ensure any personal bias was brought to the forefront of the researcher’s mind. On return to work after each bereavement, the researcher suspended interviewing and analysis for two weeks to allow time for distancing and reflection. The researcher wrote a memo listing the main points of their own experience of end-of-life care and re-read these memos intermittently during subsequent data collection and analysis. The aim of using these personal memos was to remain reflexive and ensure that identification of emerging categories was grounded in the data rather than the researcher’s personal experience.

5.17.11 Achieving data and theoretical saturation

The principles identified by Francis et al. (2010) and discussed in 3.10.3.3 informed the judgement of data saturation in this study. The initial sample size was stated *a priori* to the ethics committee (see 5.5). This was intentionally left large to allow for the researcher's inexperience with grounded theory, the diversity of participants and the breadth of the research questions, all of which might increase the required sample size. Nevertheless the caveat 'or until data saturation' was added. The researcher undertook ten interviews in each group as an initial analysis sample, and then judged that more interviews were required. As reported (see 5.17.6) a second coder reviewed and confirmed the developing categories and themes. The researcher set the stopping criterion i.e. the number of interviews required to confirm informational redundancy, at three interviews. Therefore as reported in 5.19, 23 healthcare professional interviews and 15 relatives' interviews were required before data saturation was achieved i.e. no new concepts or categories emerged from the data. However, because of the limits to sampling reported in 5.8, further development of theory may have occurred if theoretical sampling had been possible. Therefore it is not possible to state definitively that theoretical saturation was achieved in all themes.

5.17.12 Member checking

As discussed in Chapter Three (see 3.12), death and dying are sensitive research topics (Johnson and Clarke, 2003) and bereaved individuals are a potentially vulnerable research population (Pleschberger et al., 2011). Therefore the researcher wished to avoid distress for participants. The researcher sought to balance the need for study credibility with the duty of non-maleficence to participants. Therefore several measures were adopted that would maximise credibility without distressing participants. These were: using a maximum variation sample, triangulating between data sources, having a coding reviewer, examining negative cases and reporting verbatim quotes (see 3.11.2).

Care was required in this study to ensure that member checking did not cause distress to bereaved participants or make unreasonable time demands on healthcare professionals who participated in interviews. The issue of member checking and non-maleficence is discussed in 3.11.2. Consequently in this study intra-interview member checking as defined by

Thomas (2006) was used, where uncertain or contradictory statements made by respondents were clarified by the researcher during interviews and transcripts were not returned to participants for checking. A stakeholder group was sought to give views on the emerging themes. It was not possible to source a suitable local group of relatives and so the study themes were reviewed by the six study grantholders, five of whom had not been previously involved in the analysis and were lead healthcare professionals in the study's stroke units. The themes were also shared and tested in a meeting with members of a managed clinical network for stroke. Stakeholders were presented with themes and data but blinded to the study sites. The stakeholders confirmed that the themes accorded with their own experiences while affording deeper insight into their practice in end-of-life care. At the end of the study a lay summary (see Appendix 27) was posted to relatives who at interview indicated they would like to know the study findings.

5.17.13 Data entry and analysis of VOICES II survey data

The anonymised data were entered on a password-protected university computer using study numbers as identifiers. The electronic data and paper VOICES II forms were stored under the same governance and security as the interview consent forms and transcripts (see 5.16). There were no missing data because the questionnaire was administered face-to-face, although some participants chose not to add additional free text comments.

The fixed-choice responses were coded and entered into SPSS 19 as nominal variables. Simple descriptive analysis was used to calculate frequencies and percentages of responses. The sample was too small (n=17) to cross-tabulate data meaningfully from the different study sites. Free text data were entered on an Excel spreadsheet and organised by respondent and question. This allowed the researcher to see the spread of responses to each item and from each respondent. Long free text responses i.e. more than two to three sentences were transcribed from the interview recording to augment the interviewer's written notation. Later in the study, when themes were beginning to emerge, relevant VOICES II free text responses were added to other NVivo interview data, where they were used to enrich themes. Otherwise the free text responses were used as context to understand the quantitative VOICES II responses, and are presented in 5.29.

Findings

5.18 Recruitment

In total, 125 invitations were issued and 53 individuals responded positively (see Table 5-5). However, the total number of participants was lower because of attrition and purposive sampling. Two relatives could not be interviewed face-to-face because they lived abroad and remote interviewing was unsuitable given the sensitive topic and absence of ethics approval. A further three relatives did not respond to the researcher's contact to arrange interviews and one did not attend an arranged interview. Five registered nurses and two healthcare assistants were excluded through purposive sampling. Response rates were noticeably higher among relatives than healthcare professionals, as were refusal rates although the total numbers of refusal were small. Ultimately 40 respondents participated in 38 interviews. Although there were 17 relatives, the group included one husband/wife pair and one sibling pair. These pairs were interviewed together. Therefore the relatives' interviews concerned the care received by 15 patients.

Table 5-5 **Numbers of invitations to participate, response rates, attrition following recruitment and final interview totals, by participant group**

Event	Total n (%)	HCPs n (%)	Relatives n (%)
Invitation letter(s) sent	125	94	31
No response to first or second invitation	67	62	5
Negative response (declined)	5 (4.0)	2 (2.1)	3 (9.7)
Positive response (response rate)	53 (42.4)	30 (31.9)	23 (74.2)
Excluded through purposive sampling	7	7	0
Excluded because lived abroad	2	0	2
No response to further contact	3	0	3
Did not attend arranged interview	1	0	1
Participated in interview	40	23	17
<i>HCP – healthcare professional</i>			

5.18.1 Characteristics of respondents

5.18.1.1 Relatives

Relatives were interviewed a median of 5.9 months after their bereavement (min 4.7, max 7.4 months).

Table 5-6 presents demographic characteristics of participating relatives and reports interview venues. Most interviews took place in participants' homes which ranged socioeconomically from local authority flats to a country estate. All participating relatives were ethnically white Scottish or British.

Table 5-6 Demographic characteristics of participating relatives, relationship to patients, and interview venues

Demographic variable – relatives (n=17)	n (%)
Sex Female	9 (52.9)
Age <50 yrs 50-69yrs 80-89yrs	3 (17.6) 13 (76.5) 1 (5.9)
Relationship to patient Spouse Son/daughter Niece/nephew Son in law	1 (5.9) 14 (82.4) 1 (5.9) 1 (5.9)
Interview location Participant's home Participant's place of work University office	15 (88.2) 1 (5.9) 1 (5.9)

5.18.1.2 Healthcare professionals

The participating healthcare professionals were generally experienced in stroke care, reporting a median duration of 9 years working in the specialty (interquartile range 4.5 - 14 years). A range of disciplines took part in the study, of varying levels of seniority and with varied education in end-of-life care (see Table 5-7). Almost two thirds of healthcare professionals had received some training in using the LCP. All interviews took place in the study stroke units, either in family rooms, empty side rooms or in ward offices.

Table 5-7 Demographic and educational characteristics of healthcare professionals

Demographic variable - HCPs (n=23)	n (%)
Sex	
Female	18 (78.3)
Discipline	
All nurses	9 (39.1)
Charge nurse	4
Staff nurse	5
All doctors	9 (39.1)
Consultant	5
Registrar	3
FY1	1
Healthcare assistant	2 (8.7)
Speech and Language Therapist	3 (13.0)
Education in end-of-life care	
Hospice experience	3 (13.0)
LCP seminars	14 (60.9)
Postgraduate module (palliative care)	5 (21.7)
LCP 'champion' training	2 (8.7)
<i>HCP – healthcare professional</i> <i>FY1 – Foundation Year 1 (junior doctor)</i>	

5.18.2 Support required by interview participants

Most interviews flowed well, with several items being covered spontaneously i.e. not requiring to be elicited. As opening questions, healthcare professionals and relatives were asked to describe their experience of end-of-life care in stroke. Healthcare professionals usually gave short general impersonal descriptions of the challenges of providing end-of-life care. In contrast, relatives gave full narrative accounts of their experience, often from stroke onset through stroke unit admission and to the death of their relative. They told their story, whereas healthcare professionals talked about key issues. Some relatives commented that they enjoyed the interview or that it was their first chance since the bereavement to discuss their experiences.

Several relatives became distressed and cried during interviews but all declined the offered break, preferring to speak through tears. No healthcare professionals became distressed during the interviews. All interviews ended on emotionally neutral 'safe' topics and no

participants remained distressed at the end of interviews. No participants withdrew from the study. The researcher left leaflets for the bereavement charity CRUSE with two relatives. The researcher was never required to contact GPs or supervisors with concerns about participants' wellbeing.

5.18.3 Influence of the researcher

Participants were aware that the researcher was a health professional and studying for a PhD. As with the health professional researcher in Richards and Emslie (2000) (see 3.10.2.9), some participants asked clinical questions and some asked for information about health services. Others expressed opinions about care quality and these are presented in 5.22.

5.19 Description of the data

In this section, both numerical and textual (or thick) descriptions of the data and study settings are provided. First, a numerical description is reported.

Sandelowski (2001) recommended that qualitative researchers use numbers to describe and quantify their data when reporting findings, as part of an audit trail. Reporting numerically, Sandelowski argues, also helps to demonstrate the magnitude and complexity of qualitative investigations. Accordingly, the volume and distribution of qualitative data are reported in the following section. Further, Sandelowski (2001) also suggested that the frequency of participants' statements about their experiences should also be reported. This lessens the risk of researchers giving undue weighting to outliers and indicates the prevalence of issues, thereby enabling readers to gauge the trustworthiness of the researcher's conclusion. Therefore in the sections of this chapter where interview themes are reported, frequencies are reported for transparency.

5.19.1 Data volume and distribution among participants

In this study, approximately 117 pages (A4) of field notes, coding journal and memos were generated. Additionally the interviews themselves generated a large volume of transcribed data for analysis (see Table 5-8).

Table 5-8 Total hours spent interviewing and volume of data generated, by study site

Study site	Interview hours	Typed A4 pages	Words
Site A	04:52	74	39,729
Site B	13:06	166	98,877
Site C	07:04	96	57,052
Site D	03:10	40	24,963
Total	28:12	376	220,621

The largest number of participants came from Site B. Nevertheless, there was a reasonable spread across sites in keeping with the generation of a maximum variation sample (Table 5-9). The preponderance of doctors and nurses in the sample reflects the purposive and theoretical nature of the sampling i.e. sampling to answer the research question and develop theory. These participants had the greatest knowledge of end-of-life care and decision-making. Healthcare assistants and speech therapists were peripherally involved in these clinical issues so were not sampled extensively. Similarly, Site D had fewer participants because it was accessed later in the study when data saturation was being reached.

Table 5-9 Spread of participants across study sites, and totals in each site, by participant category

Participant category	Site A	Site B	Site C	Site D	Total per site
Doctor	3	3	1	2	9
Nurse	2	3	3	1	9
Health Care Assistant	0	1	1	0	2
Speech & Language Therapist	1	1	1	0	3
Total for HCPs	6	8	6	3	23
Relatives	3	8	4	2	17
Overall total	9	16	10	5	40
<i>HCP – healthcare professional</i>					

Although more healthcare professionals than relatives participated, the overall time spent interviewing each group was roughly similar, as Table 5-10 shows. Although a greater volume of interview transcript data was generated with healthcare professionals, the total shown for relatives in Table 5-10 does not include the VOICES II survey data.

Table 5-10 Total hours spent interviewing and volume of data generated, by participant group

Participant category	Interview hours	Typed A4 pages	Words
Doctors	05:57	90	48743
Nurses	05:07	90	49840
Healthcare assistants	01:03	17	8790
Speech and language therapists	01:45	28	15,522
Total for HCPs	13:53	225	122895
Relatives	14:19	151	97726
Overall total	28:12	376	220,621
<i>HCP – healthcare professional</i>			

5.19.2 Thick description of the study background

In 3.11.2.2, the use of thick description to enhance transferability is discussed. According to Holloway and Wheeler (2010) thick description shares the participants' context with the reader, describing the study location and participants and using descriptive data collected by the researcher including verbatim narratives from participants. In this thesis a profile of the stroke units involved in the study is reported in 4.1.1, indicating bed numbers and the nature of stroke services provided. The profile, coupled with the reports of participant characteristics in 5.18.1 contributes to thick description. Additional text data are now reported. When data analysis was complete, four free nodes i.e. standalone data categories remained which contained relevant background information but had not been coded into the major themes. These related to the adverse media coverage of the LCP, stroke unit infrastructure, staff education on the LCP and supporting staff. These categories contained rich data about the study context and are presented in the next sub-sections.

5.19.2.1 Influence of LCP media coverage

Around half of healthcare professional participants (n=13) were aware of negative media coverage surrounding the LCP, as were three relatives interviewed late in 2012. Of the seven healthcare professionals not aware of coverage, five were speech and language therapists and healthcare assistants i.e. staff groups reported by interview participants to have limited involvement in end-of-life decision-making (5.7.3.2).

All the healthcare professionals who were aware of the media reports, and one relative (a registered, practising nurse) who had heard the reports, rebutted the coverage, arguing that the LCP was helpful for providing end-of-life care:

“I think in certain quarters it’s very much viewed as a ‘Liverpool Care Pathway is a Kill Them Off As Quick As Possible’ pathway and close the door and don’t do anything, but it’s not like that in practice. When you use it, you get to use it, you see what it can do, I’m actually very supportive of it; I think it’s improved the way we look after people in the final hours or days or weeks of their life, because we will stop jaggging them unnecessarily; we will stop doing blood pressure measurements or urine volumes or all those sorts of things that ... are not important anymore.” (Doctor 5)

This group described having professional knowledge of end-of-life issues and said that once this knowledge was carefully shared with families they usually agreed with LCP use:

“But I think if you show them [*families*] it, I think that quite often helps.
Interviewer: What - actually show them the LCP documents? “Yeah. ‘This is what we’re looking at now, like looking at pain, agitation.’ They kind of went, ‘Oh right.’ I don’t think they realised a lot of it. I think it’s pure education and at the moment all of the messages people are getting are bad.” (Doctor 7)

Nevertheless, some healthcare professionals reported instances where negative media coverage stimulated family discomfort with, and hostility to, LCP use. A field note made approximately halfway through the data collection period illustrates (see Box 5-6).

Box 5-6 **Field note made on 21st June 2012, reflecting on a newspaper article published the previous day**

Field note: 21/06/12

Doughty, S. "Top doctor's chilling claim: The NHS kills off 130,000 elderly patients every year." Daily Mail 20th June 2012, page 6

Note: I found out about this article on the day it was published (yesterday). I was doing an awareness-raising session about the study at a ward meeting in Site D. The senior charge nurse had organised it. When I introduced my study and mentioned that I was looking particularly at the use of the LCP there was a sharp intake of breath from the nurses. They asked if I had seen that day's Daily Mail, because they had been handed it by concerned relatives of an LCP patient currently on the ward. "This doesn't make our job easier." However, the issue seemed to make the staff feel positively about the study; they said they would be happy to help and saw it as timely and useful.

Healthcare professionals actively addressed families' discomfort about the LCP. Doctor 3 described exploring reasons for discomfort:

"We do also have circumstances where family members throw their hands up in horror and say, "That's euthanasia; I've read about that in the Daily Record, you're not putting them on that pathway thing." *Interviewer: "How do you handle that?"* "Well, you can explore what their understanding of it is and what do they understand about palliative measures, are they aware of everything clinically that's wrong with that individual? Maybe they've had a bad experience before." (Doctor 3)

Ways in which healthcare professionals negotiated family discomfort or hostility towards the LCP are reported in 5.24. The reports of media coverage occurred throughout the data collection period. However, towards the end of data collection several healthcare professionals said they had begun avoiding using the pathway because of the media coverage. Either families were too upset by it or the healthcare professionals were worried about complaints and possible litigation. Yet at that time, and in fact during the entire data collection period, the Scottish Government (2012) position was that the LCP could remain in use (see 2.15).

5.19.2.2 Stroke unit infrastructure

Staff in all sites reported limitations in stroke unit infrastructure that hampered the accommodation of families and provision of privacy to dying patients. Generally, healthcare professionals reported difficulty in accessing quiet space to speak with families

uninterrupted, and catering facilities and overnight accommodation for families were patchy. Two units (A and D) had a designated room for families within the stroke unit. Neither room could accommodate large families or was suitably equipped for overnight stays. In Site D the family room also doubled as a staff room and a meeting room. In Site C, there was no designated family room in the ASU but across the hospital there were a handful of rooms that any family could access on a first come, first served basis. Site B had no family room at all. Healthcare professionals reported trying to compensate for the lack of resources by providing easy chairs and blankets for relatives staying overnight at the bedside, asking families to treat the patient's room as their own and by providing practical help like parking vouchers or access to takeaway food deliveries.

Healthcare professionals in sites A, B and C also reported having limited numbers of single rooms which reduced their ability to provide privacy for dying patients. Single rooms had to be prioritised for patients with infections, limiting their availability for the dying. Occasionally if more than one stroke patient was dying, staff had to make further difficult decisions about priorities:

“We’d two gentlemen dying at the same time. And we had to make a decision who gets the single room. And it was the person who had the most family. I wouldn’t like to be standing behind a curtain, my father dying and hearing all the conversations going on round about.” (Health Care Assistant 1)

Two relatives reported infrastructure limitations that caused discomfort or anxiety for them and the patient. One incident concerned broken equipment and the other a lack of space and security staff to deal with a violent patient. Most relatives, however, described efforts by stroke unit staff to make them comfortable at their family member's bedside.

5.19.2.3 Educating staff to use the LCP

Healthcare professionals in all sites reported the availability of training to use the LCP. For the majority of staff this was their only source of education on end-of-life care. Training usually operated on a cascade system, where healthcare professionals attending formal training sessions returned to their clinical area and taught colleagues who had not attended. Generally the LCP education sessions were short, lasting one to two hours. However, the use of LCP champions was also reported, where one or two designated members of staff

received longer training and took responsibility for co-ordinating LCP training and resources in their clinical areas. Training and champion roles were open to all grades of clinical staff including healthcare assistants. Healthcare professionals also reported that specialist palliative services in their hospitals provided ongoing educational support and updates.

A few participants reported difficulties with the training system, where trained champions moved to other posts or the high turnover of junior doctors created enduring training needs. Additionally, a small number (n=3) described difficulties in accessing palliative care courses unrelated to the LCP, because of lack of funding or staff shortages that prevented their release from the clinical area to attend.

5.19.2.4 Supporting staff

Across the study sites, healthcare professionals identified several organisational sources of social and emotional support for staff. These included occupational health, employee counselling, chaplaincy and specialist palliative services. However, a small number of healthcare professionals (n=5) reported that giving end-of-life care was part of the job and formal support services were not commonly used:

“There’s Employee Counselling of course, but nobody that I know of goes *[laughs]* and obviously it’s confidential anyway. But there is Employee Counselling and everybody’s aware of that. And if people wanted to go down that route then they can. But I think nursing’s very much a profession that you’re expected to take it on the chin and get on with it and that’s part of your job... And I think it’s part of being a good nurse, is to be able to cope with things. But I think your colleagues are your support mechanism, mainly. And I think we’ve got a pretty good structure in here, of people being able to talk about anything, really, to do with patients and to do with how they feel about things. I don’t think anybody would go, “Oh, stop being silly,” or anything *[laughs]*.” (Nurse 4)

Around half of healthcare professionals (n=14) reported similarly about support from colleagues, saying that they gave or received emotional support on an informal basis from other healthcare professionals:

“I’ve looked after a patient just before Christmas, who was in his forties and died on the day of admission, and the family were just the most grief-stricken family I’ve seen. Myself and the consultant and the nursing sister were pretty

upset by it, so we had an *[laughs]* unofficial debrief just to, I suppose, cry a little bit, just talk about it.” (Doctor 4)

One charge nurse said they actively encouraged debriefing at shift handovers as a way of supporting staff and one consultant identified multidisciplinary team meetings as a forum for “the briefest of debriefing... a shared acknowledgment of something that’s difficult” (Doctor 1). Four healthcare professionals in three sites reported that staff could experience more distress in caring for younger patients or for patients who had long stays that allowed emotional attachments to form.

5.20 Thematic findings

According to Braun and Clarke (2013), a 'theme' is a collection of coded data relating to a key concept or topic. A theme may include minor sub-themes that contain data on discrete or distinct aspects of the theme. In this study, the researcher identified subthemes that were sufficiently distinct almost to stand alone. Yet they were so relevant to the parent theme that the researcher classified them as related in a key way. By contrast, an overarching theme incorporates a concept that runs through several themes (Braun and Clarke, 2013). In this study, two overarching themes, five themes and five subthemes were identified (Box 5-7) and are presented in the following sections.

Overall, providing end-of-life care after acute stroke was complex and often fraught with uncertainty regarding diagnosis and outcome. Care was generally reported as good. Specific reports of the LCP were less prominent than reports of stroke-related issues. Families played an active role in asking for care, giving care directly and organising care. The decision to use the LCP involved multiple stages and families were usually involved in decision-making. The duration of the dying process was potentially distressing for both healthcare professionals and relatives, particularly in relation to feeding issues. The way in which healthcare professionals provided information resonated with families and for some relatives questions about place of care endured months after the death of their family member.

Box 5-7 Interview themes including subthemes

Overarching themes Difficulty and uncertainty Care quality
Themes Active families Deciding is “a series of crucial steps” <ul style="list-style-type: none">• Recognising dying (<i>subtheme</i>)• Negotiating (<i>subtheme</i>)• Decisional responsibility (<i>subtheme</i>) Prolonged dying <ul style="list-style-type: none">• Dysphagia and feeding decisions (<i>subtheme</i>)• Managing expectations (<i>subtheme</i>) Pro-active information-giving Wondering about home or hospice care

5.21 Difficulty and uncertainty

Difficulty and uncertainty was identified as an overarching theme because it affected several other themes. Deciding end-of-life care, witnessing distressing symptoms and death after stroke, exchanging information and considering place of care were all described as difficult issues that were affected by uncertainty. Uncertainty hampered prognostication, decision-making and the ability to elicit patients’ preferences and plan care accordingly.

Several of the clinical features of stroke brought particular difficulties to end-of-life care, reported by both relatives and healthcare professionals. Half of all participants (n=20) described specific clinical features of stroke that heightened difficulties. For example, recognising dying was said to be difficult (see 5.24) because stroke was a fluctuating condition with an uncertain outcome in comparison with other conditions such as cancer:

“[Interviewer: How do you know when a stroke patient is in the last hours or days of their life?] I think that’s incredibly difficult. I think that’s the single biggest problem with the whole concept of end-of-life care, palliative care in stroke. Often the model which is designed for progressive malignancy doesn’t really work well for a condition that fluctuates, and is unpredictable... The one

thing that would maybe make a difference is if you could really accurately predict on admission, but I just don't think you can do that." (Doctor 1)

Four healthcare professionals described difficulty with managing interdisciplinary disagreements about managing end-of-life care, usually relating to the recognition of dying and the point at which end-of-life care should begin. Distinguishing clinically between features of severe stroke and those of impending death was a challenge:

"It can be quite difficult because quite often we have patients who are not at the dying stage and they are kind of similar to patients who, who would be dying; they're not very conscious or not swallowing because a stroke's taken away so much of their mobility and their swallow and their speech, so it's quite hard generally." (Nurse 8)

The fact that death after stroke was not restricted to elderly patients was distressing for some. Additionally, seven participants spoke of difficulties with trajectories of dying. While one doctor reported that managing end-of-life care was easier for patients who died rapidly post-stroke, one relative and three healthcare professionals said that the sudden onset of stroke and subsequent rapid death was particularly difficult:

"Quite often it's younger people and it is quite sudden and they might be somebody that's not really been ill before [*laughs softly*], was driving their taxi earlier in the day and rightly or wrongly I think it's more difficult for all of us to accept that younger, previously well people are suddenly dying. I think it's harder for us as health care staff to maybe bring it up, as well, and to acknowledge that this 44-year old is dying, and quite soon." (Doctor 4)

Conversely, difficulties were also reported where dying was seen as prolonged and these are reported in 5.25. Both relatives and other staff were said to require additional support in such uncertain situations.

"... It became clear that this would be the final event. The problem was that she took seven days to die... nature had to take its course. We didn't know how long that would be. It was longer than we anticipated... I did have to provide reassurance to my brother and others that everything was being done that could be done." (Relative 9)

Reports of prolonged dying trajectories were often associated with descriptions of difficult decisions about feeding. These decisions usually related to withholding or withdrawing feeding and occasionally deciding whether to accede to patient or family wishes and provide comfort feeding (feeding dysphagic patients small amounts orally for comfort in the presence of an acknowledged risk of aspiration). Where patients' wishes were clearly

known, following those wishes could sometimes be uncomfortable, if the wishes ran counter to healthcare professionals' instincts. For example competent patients occasionally refused feeding or patients/families requested oral feeding for comfort in the presence of aspiration risk:

“We’ve ... had patients who just want to have a cup of tea [*short laugh*] ... and the family don’t want to deny them that, and if you think it’s their last few days then if that’s the decision that’s been made then I suppose that’s a right that they have. It’s a hard one.” (Speech and Language Therapist 3)

Very few healthcare professionals reported discussing end-of-life issues directly with patients. Although one doctor reported that patients generally handled such rare conversations well, he reported (and displayed at interview) some discomfort with the topic of withdrawing treatment:

“It’s always very difficult to approach patients and talk about these sorts of things but I have been surprised the number of times that I’ve done it that patients’ responses to it have been very honest and very open and very candid, and been done quite calmly. So that surprises me. That you can have that discussion with a lot of the patients who don’t have any capacity issues or who are still able to communicate with you. So that’s quite, that’s quite uh, it’s quite uncomfortable to have that discussion but again it’s quite – [*scratching leg*] I don’t know – the response [*scratching leg*] is quite unusual [*scratching leg*] – well, well - I’m saying ‘unusual’ – but I find that response, that they’re able to reason like that [*scratching leg*] quite, um quite, I don’t – quite thought-provoking [*laughs*]. Probably that’s the best word to use for it.” (Doctor 5)

Healthcare professionals generally reported it was difficult to establish patients’ preferences for end-of-life care because of the prevalence of cognitive and communication problems. No families or healthcare professionals reported patients with ‘living wills’ or advance directives in place. However, families often informed the stroke team about patient preferences:

“Sometimes you don’t get the chance, as again, with terminal illness you get to, [*establish the*] the patient’s preferences and things, and I think when the patient’s aphasic sometimes you can’t get to know that. You rely heavily on their, their family telling you... Such as you know how they would feel about you know sustaining themselves artificially if they had any strong preferences on different things. And yeah I think aphasia and the swallowing, aphasia and dysphagia are - I think they make stroke different from anything else...” (Nurse 2)

Discharging patients for end-of-life care at home was reported to be difficult both to discuss with families and to achieve. One nurse said the issue was difficult to discuss because sometimes family preferences could not be accommodated and requests would have to be declined, creating tension. Several healthcare professionals reported the infrastructure for providing end-of-life care at home for stroke patients was poorer than for cancer patients and this is reported in 5.27. Generally stroke patients were described as less suitable for end-of-life care at home than patients dying from other conditions.

Across sites, the majority of healthcare professionals (n=12) said that they occasionally requested support from specialist palliative care services. This was most commonly for advice on managing symptoms such as pain, nausea or seizures, or for input at meetings with families to decide issues such as feeding or place of care. A further nine healthcare professionals said they rarely or never involved specialist palliative care.

In summary, stroke-related challenges were said to affect multiple aspects of end-of-life decision-making and care. Healthcare professionals often handled such challenges without support from specialist palliative care services. The difficulties and uncertainties affected several of the themes which are reported in the next sections of this thesis, particularly those related to recognising dying (see 5.24) and prolonged dying (see 5.25).

5.22 Care quality

Care quality was identified as an overarching theme because it was threaded through several other themes. Participants discussed their satisfaction with multiple aspects of end-of-life care such as decision-making, information exchange, physical care of patients, family support, place of care and the LCP itself, expressing both positive and negative views.

Both bereaved relatives and healthcare professionals discussed the quality of care. Around half of healthcare professionals (n=11) reported that the LCP had not introduced new care but simply formalised existing good practice:

“But I find that since the LCP came in it’s been better, because we’re all aiming for the same goal, hopefully at the end of the day. But prior to it coming

in we did do it anyway, it just wasn't in, we just didn't have the paperwork if you like *[laughs]*.” (Nurse 3)

Nevertheless most (n=20) healthcare professionals felt the introduction of the LCP was generally beneficial in ensuring good quality end-of-life care for dying stroke patients. Some healthcare professionals (n=7) said the LCP triggered them to address issues that might otherwise be overlooked, such as discussing spiritual needs with families. Nine healthcare professionals also said that using the LCP clarified their clinical thinking:

“If I was at the end-of-life, do I really want a full scrub bed bath? ... Is it appropriate? Is it not? So I think it's probably made us – we don't give less care but it's made us think about the care we're giving. It's not, 'We have to do this.' Abbreviate to: 'What we really need to do, to keep the patient comfortable.’” (Nurse 1)

Two healthcare professionals expressed reservations about the LCP because they recalled associations with the prolonged deaths of specific patients. The theme of prolonged dying is reported in more detail in 5.25.

Generally although most relatives could define what the LCP was, they did not often refer to the LCP during their interviews and their praise or criticisms of care did not usually include the LCP, a point captured by one healthcare professional participant:

“*[Interviewer: What do you think is the impact of using the LCP?]* I guess it probably makes the whole fact that we think somebody's dying more obvious... I don't think people - it wouldn't surprise me if families didn't really notice too much about it. I don't think the first thing they think is, 'Oh, he's on the LCP.' I think you know, they think, 'He's dying.' I'm not certain it's that big an issue for families, but the press might suggest otherwise...” (Doctor 6)

Overall, families described the quality of end-of-life care as good. Relatives were generally appreciative about the care their family member received and six described making gestures of thanks to the study stroke units. These gestures included writing cards or letters, giving gifts of food to unit staff or making donations to unit funds. All relatives identified positive aspects of care, particularly physical care such as gentle handling of patients, good provision of hygiene, rapid response to reports of pain, regular positional changes and use of single rooms. Yet many of the reports focused not on care given to patients but on the ways in which staff had supported and helped families themselves. Six relatives said that staff had accommodated their large families, offering open visiting and

co-operating with the agreed family network of communications. Most relatives were offered food or drink, help with parking, overnight rooms, easy chairs, beds, pillows or blankets:

“I just thought, ‘Gosh, you couldn’t have got better care anywhere.’ My daughter and my daughter-in-law, they stayed three nights with him in the hospital, and they, just the night staff were great; gave them relaxers – these chairs, each side of the bed, so they could sort of relax and be there; and included them if they were sending out for something to eat for themselves...”
(Relative 12)

Positive reports about care often reflected personal connections made between families and staff. Several relatives recalled how staff had cried and hugged them when their family member died. The majority (n=12) reported that healthcare professionals were understanding, friendly and kind:

“..They listened, they understood. I explained to them about my family and if they could just speak to me or my ... sister; if I wasn’t available they could speak to [*names sister*]. And they totally understood all of that. They were helpful to the family, helpful to me as well as to my mum. Which I thought was tremendous.” (Relative 4)

Eight relatives said healthcare professionals were good at explaining day-to-day care as well as more major care decisions, and four were particularly satisfied when healthcare professionals avoided jargon:

“The nursing staff and the doctors, every one of them spoke to you in a language that you could understand, you know. Obviously when they were speaking with each other they were sort of conversing in their own terms, you know, but it was all made dead simple so you could understand what they were doing with my mum. ‘This is for the purpose of such-and-such; this is making sure she’s comfortable. We’re gonnae move her – could you give us couple of minutes and just step out? We’re gonnae move her and make sure she’s not getting any bedsores.’ So we could see that it was good care and attention she was getting and that was comforting for us to know.” (Relative 3)

Aspects of care quality were evident in several themes, with generally positive and some negative aspects being described by participants. For example, relatives were pleased when healthcare professionals enabled them to give care, a feature of the theme entitled ‘Active Families’ (see 5.23). Similarly, the manner in which staff sought out families to impart information, or failed so to do, was reported as a positive or negative experience of care and emerged in the ‘Pro-active Information-giving’ theme (see 5.26).

Although able to identify some good quality aspects of care, three participants were generally negative about their experiences. Their common sources of dissatisfaction were poor primary care peri-stroke and receiving inadequate or inaccurate information during the stroke unit stay. Two of these negative cases were also unhappy about their role in decision-making and this is reported further under the subtheme entitled ‘Decisional Responsibility’ (see 5.24). Both these participants were nurses, one practising and one retired. While both gave some positive descriptions of physical care (“I mean his end-of-life care was very – was good.”- Relative 7), they also criticised care and communication in the light of their own professional experiences and standards:

“Now one of the nights that I stayed with my mum, they used to disappear during the night to *[other part of stroke unit]*. Now, I’m not arguing with that. I know they need breaks and everything else but never in my day would that have been allowed, that you could go and leave a ward empty... And usually at night there only ever were two on... I’m not saying that is a lot of staff, I know it isn’t but in my day this wouldn’t have been allowed... And as I say, I trained in [Site B]. And when I look at them now I think to myself, ‘I don’t understand them at all, I really don’t.’” (Relative 1)

The third negative case reported several sources of dissatisfaction with care. These included a serious drug administration error (off-site), being given a specific but inaccurate prognosis of survival and not receiving clear warning about the possibility of dying:

“It’s just hard that you know basically the hospital should be saying to you, ‘We’re just going to let your mum die now.’ But they don’t put it like that. They put it a more flowery way. So there was no easy way round it. *[Interviewer: So what sort of flowery way did they put it, then?]* ‘If your mum’s not taking food, your mum’s not improving, she’s not getting any better – she probably could stay like this forever, possibly - she’s had a really bad stroke.’” (Relative 15)

In summary, healthcare professionals reported that using the LCP helped to maintain a good quality of end-of-life care. Most relatives discussed care quality without mentioning the LCP specifically, and care quality was generally described as good. Families appreciated the physical care given to patients but also the way in which healthcare professionals supported them as relatives, in terms of communication and practical needs. Descriptions of poor care quality tended not to involve inadequate physical care of patients, but rather, described situations where there was less personal connection between families and staff or where interactions between families and staff were unsatisfactory. The

small number of dissatisfied relatives mainly reported concerns about their role in decision-making and information-giving.

5.23 Active families

All relatives and eight healthcare professionals described the active role played by families when stroke patients were dying. Relatives often (n=14) asked staff for specific items of care, most commonly pain relief (n=5). They also asked for mouth care, religious care, single rooms, or raised concerns about feeding. Two relatives reported that they were first, ahead of the stroke team, to suggest using the LCP:

“We did ask a couple of times about the Liverpool Care Pathway and because I’d read that it kicked in at a certain time we were saying, “Is he on it?” and they were saying, “Well, when your father indicates, or when we feel that he is becoming distressed we will manage it.” (Relative 5)

Relatives (n=7) gave hands-on care to patients, most frequently feeding or giving drinks (n=4) or mouth care (n=3). Five arranged religious care without the help of stroke unit staff. Many (n=14) spoke of negotiating with other family members; common topics for negotiations were visiting arrangements, communicating information obtained from staff and occasionally (n=4) disagreeing over decisions taken.

Many relatives (n=14) actively sought information on prognosis, scan results, feeding, clinical progress or medication. Several reported a need to ask questions repeatedly, or return to staff with additional questions. Relatives employed various strategies to obtain information. Some (n=7) had to negotiate access to consultants or senior nurses in order to ask questions. Fewer than half (n=6) used information leaflets, either given to them by staff or which they found on display. More relatives (n=7) did not remember seeing leaflets or finding them useful. Around half (n=9) of relatives informed themselves about the LCP without help from the stroke unit, using the internet or existing social networks that included friends, colleagues or family members with medical knowledge:

"I got the Pathway information as I said, and I went onto the internet, and spoke to people who had already been trained on it in the care home. The care home were really really good, you know. *They* explained to us about the Pathway as well. So when we were briefed by the hospital, we pretty much were already up to speed with it." (Relative 5)

Although healthcare professionals reported that breaking bad news was a key part of their role in end-of-life care, around half of relatives (n=9) recognised their family member was likely to die, without explicit explanation by staff:

"Now, nobody told me he wasn't going to come home... and I'd been in to see him and I was sitting in here myself and it just – it was like – I can't explain – it was like a blow – a sudden realisation. And nobody had told me. I thought, 'He's not going to come home; he's not coming back home.'" (Relative 12)

Some relatives recognised the impending death by reading non-verbal cues from healthcare professionals' language or behaviour or by observing what happened with other patients who died:

"I would say it was only the last day it became apparent that she started – her breathing changed, and – something about her face changed. I don't know what – it became more sunken and she just had that look. We'd actually – it was unfortunate, because the three side rooms, we'd seen a few people come and go... you could see them and hear them, their breathing changing; they seemed to go a lot quicker... maybe about three people went, and you could hear them breathing regularly and then you'd hear their breathing [*sharp intake of breath*] going a bit different... And then you would see them disappear, you know, the curtains would go and they'd go." (Relative 16)

Three relatives deliberately tried to build good relations with the staff or avoided alienating staff, in order to procure the best care for their relative:

"I think that if you treat the staff with respect and politeness, that it'll repay itself many-fold." (Relative 14)

In short, relatives were often active in securing or providing some end-of-life care for patients, including the co-ordination of religious care. Additionally, while many relatives engaged with stroke unit staff to obtain information, many also operated independently to source information for themselves or to make their own deductions about dying. Written information appeared useful to a minority of relatives. A small number of relatives actively monitored care or tried to build the best possible relationship with staff in the hope of maximising care quality.

5.24 Deciding is “a series of crucial steps”

Reports from most healthcare professionals (n=20) indicated that deciding to use the LCP was a multi-phased linear process: "...there's a series of crucial steps but not one crucial step" (Doctor 1). Participants described steps in the decision-making process that followed each other in logical sequence. However the stepped process could also be blocked by events that hindered healthcare professionals and families reaching agreement on the patient's preferences for end-of-life care. These steps and barriers are depicted in Figure 5-1 and are now presented in more detail.

Recognising dying and excluding reversible causes of deterioration such as sepsis or renal failure were the first steps. The recognition of dying emerged as a key subtheme and is reported in the next section. Some concerns were raised about using the LCP model to recognise dying following acute stroke, which made healthcare professionals particularly careful in judging when patients were dying:

"I think a lot of our well stroke patients could fit the criteria for the LCP, because they're bedbound and they can't take tablets... I always find that quite hard. We could be putting well patients - I know we don't – but really, according to those criteria we could be. It's important to get a full holistic assessment, and again make sure you've excluded all kind of reversible causes." (Nurse 2)

The next step was raising discussion with the wider multidisciplinary team. Most healthcare professionals (n=17), including six of the nine doctors, reported that nurses were usually first to take this step. In general, nurses as a group, rather than doctors, therapists or families were seen as the main instigators of discussions around end-of-life care for specific patients. The reason for this was mainly ascribed to their location, as being with the patient for the greatest time in comparison with other professional groups:

"... I think in general nursing staff are quite pro end-of-life care pathways; they'll recognise pretty quickly when it's appropriate and they're quite keen to instigate it... I suppose I mentioned nursing staff cause they're the ones that are there, all day, every day... I think nursing staff are pretty good at pointing it out and saying, 'Do you think we should be considering a pathway for these patients?'" (Doctor 4)

In contrast, the participating healthcare assistants and speech and language therapists were clear that their role in decision-making was peripheral or non-existent. Patients were usually discussed either during ward rounds or at multidisciplinary team meetings.

Discussions were used to establish that all team members believed the patient was dying, further aggressive treatment was likely to be futile, that the direction of care should alter and that the LCP model of care was appropriate.

An additional step was that where possible healthcare professionals attempted to elicit from patients their preferences for aspects of end-of-life care such as feeding or resuscitation and establish patients' capacity for decision-making. Yet such discussions were seldom possible because of stroke-related cognitive and communication difficulties. For most healthcare professionals (n=19) it was therefore vital to meet with families before finalising a decision to use the LCP. Such meetings were used to elicit information on patients' preferences, to communicate prognosis and outline the proposed plan of care. Nurse 1 summarised:

“As a team ... we bring it up at the MDT meeting, and we discuss it with the therapists and we discuss it with the medical staff. But inevitably the decision is down to the consultant, but it's in collaboration with the rest of the multi-disciplinary team. And then the family are involved. But we try to encourage the family to be involved at that early stage in the game.” (Nurse 1)

Although consultant physicians had the final decision, LCP use was generally seen as an issue to be agreed by all parties:

"... The difficulties, angst you sometimes get into in the management with families and with the whole team, are... often because not everyone's at the same place in that decision making and I think that's often a problem." (Doctor 1)

Many healthcare professionals (n=11) avoided diagnosing dying in the early post-stroke phase. Early judgements typically turned out to be inaccurate:

"It's not unusual for us to inherit patients who've come in, have looked awful neurologically and the family have had a very bleak picture painted to them and couple of days later, the brain swelling goes down and they actually pick up." (Doctor 3)

Hence the decision to implement the LCP typically took one to four days to enact. Many clinicians (n=13) described "waiting to see" (Nurse 4) before finalising a decision to allow a clear view of the patient's progress or response to treatment such as antibiotics to emerge. Not rushing the decision also allowed time for families to be contacted, for discussions to take place with families, for families to adjust to bad news and crucially, for agreement to

be reached among the team and between the team and families. In Figure 5-1 this consultation phase is depicted as “holding off” (Doctor 1). Where teams and families agreed, LCP implementation would proceed.

Conversely, participants described three typical situations where the LCP could not be used. In these situations an element of the decision-making process would be blocked or missing, precluding agreement. In the first situation, families might object to LCP use and this is reported under the heading ‘Negotiating’ in the following sections. Second, where patients deteriorated very rapidly over minutes or hours it was sometimes impossible to acknowledge that patients were dying and hold the necessary discussions. Third, participants reported that end-of-life decision-making was more difficult during weekends or at nights, where care was not always provided by the usual stroke medical team. Doctors covering weekend stroke care were reluctant to make decisions for unfamiliar patients hence the decision to implement LCP was usually postponed for regular stroke team review on Mondays:

"The weekend is a problem, because ... our doctors are not in the ward at the weekend; it's other consultants from other wards... and they don't want to step on somebody else's toes." (Nurse 5)

Healthcare professionals overcame the obstacle of weekends by communicating ahead:

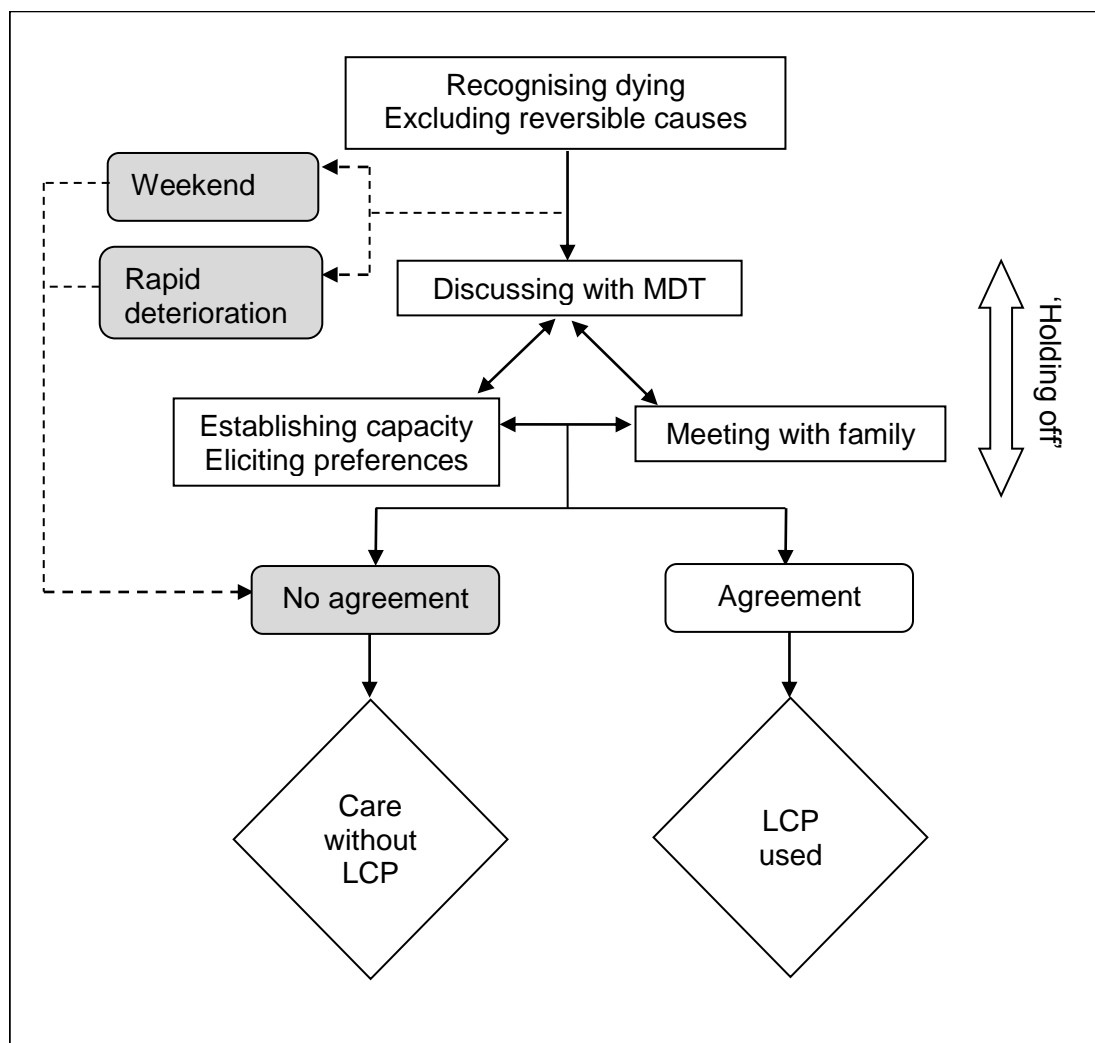
"I guess at the weekend the duty of care is just to try and get people through ... So ... we try and make sure that there's handover to the people that are coming on ... saying, “This is what's happening. If there's any further change we were thinking LCP.” (Doctor 2)

In all three circumstances, most clinicians (n=19) tried to provide high quality end-of-life care without formally adopting the LCP. Participants reported that such care was focused on stopping unnecessary treatment and observations, documenting resuscitation status and ensuring anticipatory prescribing was in place.

In summary, the decision to use the LCP was reported as an unhurried consultative process that involved multiple disciplines and patients' families. Accurate recognition of impending death was crucial and healthcare professionals allowed time for stroke-related diagnostic uncertainties to be clarified. Rapidly deteriorating clinical trajectories precluded consultation, as did weekend medical staffing. Family or team disagreements regarding patient preferences could also prevent the LCP from being used. Data relating to the

recognition of dying, subsequent negotiations and their consequences are now presented in more detail. These emerged as relevant subthemes to the overall theme of decision-making.

Figure 5-1 Flowchart showing the sequence of decision-making commonly reported by participants as culminating in the use or non-use of the LCP. The three barriers to LCP use are highlighted in grey.



Recognising dying

Recognition of impending death was described by all but one participant, a relative who was absent from their family member's bedside in the last few days of a prolonged dying process. Participants most commonly reported that changes in physiological signs such as altered breathing patterns, conscious level, blood results or vital signs could indicate the impending death of a patient. Nevertheless several participants pointed out that changes in breathing could occur late in the dying process, often after the LCP was instituted and so

altered breathing was not necessarily an indicator to commence LCP use. Participants typically took account of multiple factors in recognising dying:

“Their colour will change, their breathing quite often changes and sometimes that can be where their respiratory rate goes way high... and then the alternative, the other side of that coin is where the respiratory rate goes right down and you know it might be a form of Cheyne-Stoking breathing or something like that, but probably that’s actually nearer the very end, as opposed to the last few days, I would say, of life. But I think certainly altered conscious level, with patients. If ... you know on scan that they have a huge mass effect in their brain ... they’ve had a massive haemorrhage or something like that. The haemorrhage patients get really hot [*laughs briefly*]. In my experience I find the haemorrhage patients near the end of life are quite hot, actually.” (Nurse 9)

Seventeen healthcare professionals and four relatives reported using clinical trajectory to judge whether or not patients might be dying. This included downwards trajectories where patients showed serious clinical deterioration, or static trajectories showing persistent coma or no response to sustained treatment such as antibiotics:

"Um, just when they are not responding to treatment, so ... a lot of them die of aspiration pneumonia so say they’ve been on antibiotics, say they’ve had a week or two weeks course, and then their blood counts aren’t responding so they still have a temperature, they’re still quite unwell, they become, like their GCS begins to change, so you know, they might be quite responsive and then become quite unresponsive, their breathing becomes more difficult. Yeah." (Doctor 7)

Ten healthcare professional participants also reported that imaging results were used in judging stroke severity and hence gauging whether or not patients were likely to die post-stroke. This was particularly reported in relation to intracerebral haemorrhages which were often described using terms like “massive” (Nurse 9), “dramatic” (Doctor 2) or “catastrophic” (Nurse 3). One participant, a doctor with specialist palliative care experience cited terminal agitation as a sign that death was near.

Stroke was often described as a fluctuating condition where patients might improve or deteriorate (see 5.21). Consequently a few doctors (n=4) who visited the stroke units only intermittently reported it was difficult for them to gain an accurate clinical picture of patients’ progress or lack of it. These healthcare professionals said they would rely on multidisciplinary colleagues to supply clinical information before concluding that a patient was dying:

“So I suppose some clinical signs, some clinical parameters, radiology, and some of it’s just experience from knowing somebody’s dying. *[Interviewer: From standing at the bed?]* I think a general sense of, uh huh, of going in to see patients and what the other staff tell you, yeah.” (Doctor 4)

In addition to Doctor 4 (above) four other healthcare professionals and four relatives also drew on previous experience or intuition when recognising that patients were dying:

“There’s a change in them, and a lot of it is nurses’ gut instinct, where you have had that experience and you know that that patient has taken a change; their face becomes thinner, they don’t pass as much urine, they -there’s just a general overall change in them and having nursed them for a while you can see the change.” (Nurse 1)

Around half of the relatives interviewed said they had recognised, without being explicitly told by staff, that their family member was dying (see 5.23). Some realised because of their own previous experiences, by observing breathing changes in the patient, or by extrapolating from their observations of other patients who died. Three relatives also took cues from the clinical actions of staff:

"So we knew when the morphine dosage had to be put up it was - the time was coming." (Relative 2)

"Getting it wrong" (Doctor 9) was an issue identified by seven healthcare professionals as a source of professional concern. While it was sometimes difficult to determine if patients were in fact dying after stroke, it was also possibly mistakenly to diagnose dying, especially in the early post-stroke phase:

“It can also be very difficult to predict as well, particularly for patients who maybe have large haemorrhages. They not infrequently look absolutely terrible when they first present. It’s not unusual for us to sort of inherit patients who’ve come in, have looked awful neurologically and the family have had a very bleak picture painted to them and couple of days later, the brain swelling goes down and they actually pick up *[laughs softly]*. So we kind of deal with both sides of the coin; sometimes we think patients are dying and yet they’re not and that can lead to quite interesting conversations.” (Doctor 3)

Making prognostications about timing were also reported to be difficult. Several families had received ‘false alarm’ phone calls from the hospital when it was thought, wrongly, that their relative was about to die within minutes or hours. One relative described an adverse effect of very precise prognostication:

"The stroke, I mean four days after it... she was due to die. One young doctor said to me, "She's got four days to live," so I phoned my brother from [*another country*]. He flew across. So four days went to about, phew, a month and a bit. So the doctors are only guessing, but with a stroke you can't tell so they had to give me the worst advice, I suppose, but the more senior doctors said to me they couldn't really predict." (Relative 15)

Nevertheless failing to recognise dying was also a concern. One doctor, four nurses and one relative who was herself a nurse, believed that doctors had difficulty in admitting that patients were dying. Doctors were said to persist at times in futile life-prolonging treatments. Additionally six participants spoke of "missing the boat" (Doctor 3) or recognising dying late, which might result in the LCP being used for only a brief period of up to 12 hours.

In summary, healthcare professionals used multiple factors to judge if patients were dying after stroke. These factors included clinical facts such as physiological signs or imaging results and observations such as clinical trajectory. Healthcare professionals also drew on previous experience and intuition. Some healthcare professionals also relied on other team members for clinical information to reach the diagnosis. Family members used information from staff and drew on their own observations to conclude that their relative was dying. Recognising correctly that patients were dying was sometimes difficult and predicting the course and duration of the dying process was also challenging.

Negotiating

Participants reported that patients were often unable to communicate their preferences for end-of-life care. No participants reported patients with 'living wills' or advance directives. Only two families said that their relative decided nasogastric feeding or resuscitation for themselves:

"Right at the beginning when Mum was still able to sort of communicate by squeezing our hands, the doctor asked Mum, he didn't ask us; he asked Mum what she wanted to do, if she wanted to be resuscitated. So it was clearly between the doctor and Mum." (Relative 10)

Around half of healthcare professionals (n=12) highlighted the stroke-specific challenges in having such conversations with patients. Speed of stroke onset, cognitive and communication difficulties all precluded discussion of preferences:

"I think because it's a sudden thing, a stroke – and with them having speech problems or cognitive problems, it's very difficult for us to speak to patients about how *they* want to die." (Nurse 7)

Hence many healthcare professionals (n=18) relied on family members to tell them how patients would like to be cared for. Only two healthcare professionals described "throwing the net wide" (Doctor 2) and looking beyond families for information, by checking casenotes for information recorded during previous admissions. No healthcare professionals reported contacting patients' GPs to check if preferences were recorded in primary care notes. All relatives could tell the story of patients' pre-stroke lives and not surprisingly, they were usually intimately aware of patients' medical history and living arrangements; three lived with their family member. One participant reported having legal power of attorney over their relative's affairs. Many relatives (n=11) said they knew the patient's wishes regarding aggressive medical intervention and no patients were reported as desiring such active treatment. Only two bereaved participants had never discussed the subject with their relative. Many healthcare professionals reported that family members therefore played an important role in decision-making by informing the clinical team about patient preferences:

"So we have to take the medical knowledge that we have... and take the patient's views into consideration, primarily, but often we can't do that, so we will then go to the family and say, 'In these circumstances, has the patient ever expressed a wish that in these circumstances when things aren't going very well, that they would like... this ... option or that ... option?'" (Doctor 5)

Healthcare professionals typically asked families about their relative's attitudes to issues such as cardiopulmonary resuscitation, clinically assisted hydration or nutrition, morphine use and LCP use. Consequently the views of families were influential in clinical decision-making:

"Well I do always tend to ask the family if someone's looking very ill, or can't speak for themselves... 'What sort of person are they? What do they like? What's their view?' ... you can sometimes be surprised in that they'd say, 'Oh my goodness, this would have been unacceptable to Mum,' ... so clinically and personally that can be very helpful." (Doctor 9)

A range of family views were reported by healthcare professionals, with some families clear that their relative wished no aggressive medical treatment to sustain life while others were insistent on the reverse. Healthcare professionals said families were often concerned

about withholding or withdrawing feeding and hydration, and later in the data collection period families were reported to be concerned about using the LCP itself. Many healthcare professionals described how they addressed family concerns, usually exploring the reasons for concerns and giving information repeatedly to help families understand the rationale behind clinical decisions and try to allay family fears:

“I would try and find the time to speak to them... find a quiet room... I suppose I go along the Breaking Bad News kind of, ask them what they know is going on and how they feel about what’s been happening, what have they noticed with the patient, and say, ‘You know, this is what we’ve done but we’ve noticed as a team that things aren’t getting better, the patient’s deteriorating and we feel that the treatments we’re offering aren’t going to improve the situation or make things better and that it’s perhaps time to switch to managing symptoms and making sure the patient’s not in any discomfort or distress.’” (Doctor 4)

Nevertheless healthcare professionals described situations in which family views on specific clinical decisions remained strong with the effect that relatives could trigger or embargo certain types of care:

"Sometimes families will come and say to you, ‘Oh, I don’t want you to stop the fluids,’ and that’s just something you need to kind of need to contend with. We have on a few occasions kept fluids going and things if the family are really - they understand the patient’s dying, they understand that they want them kept comfortable - but they just feel it’s a bit too far, taking away their fluids; it’s just generally the main sticking point, that they want to keep the fluids going.” (Nurse 8)

Although making clear that they would not act against the best interests of patients, the majority of healthcare professionals (n=16) reported that they sometimes altered their usual practice to avoid upsetting families who had voiced strong views about aspects of end-of-life care. These alterations included postponing the move from active care to palliation (n=4), continuing or commencing clinically-assisted hydration (n=6), avoiding use of the LCP (n=5) or using lower than usual morphine dosages (n=1):

"And some people, even if they’re not on it [*the LCP*] and we talk to them about using Oxynorm, and they’ll ask us what that is and we’ll say, ‘Oh, it’s morphine.’ ‘Oh, I’m not having any of that.’ I had one person say that, actually. The lady that I talked about earlier, and her husband was like, ‘Oh, I don’t think she should have any of that.’ ... And we started her on a smaller dose than we would ordinarily do ... we eventually went to a syringe driver, but that was, we had to do a lot of chatting to do that.” (Nurse 9)

In situations where families objected to LCP use, healthcare professionals described using the principles of the LCP to manage care, without implementing the formal LCP paperwork. These principles often included anticipatory prescribing and withdrawal of unnecessary interventions, and did not commonly include a focus on spiritual care or communication with the primary care sector.

“...The family, we specifically discussed LCP with them and they absolutely did not want us to start it, but we still did all the – we did – but without the paperwork... But they were still on morphine and midazolam and hyoscine and all these things, and they got them as we would have given it if they had been ... so we still did what we would have done... But they felt more comfortable with that. They felt the Liverpool Care Pathway somehow was going to hasten the death and they weren’t probably ready for that... So it was quite interesting having somebody so, ‘No, I really don’t want you to do that.’” (Nurse 4)

Thus these differentiations to practice were the result of discussion and negotiations between healthcare professionals and families and reflected healthcare professionals’ attempts to accommodate proxy reports of patient preferences. Nevertheless healthcare professionals who altered their practice in this way often described the alterations as part of a dynamic process. By slowing the process, the healthcare professionals aimed to implement usual end-of-life care practices, but at a rate with which families were comfortable. It was recognised that some families required time to adjust to the fact that their relative was dying:

"...We would stop non-essential things anyway, like medicines for example, but that ...doesn’t always extend to things like stopping courses of antibiotics that you know are... not really doing anything but maybe it’s a bit too much to say to families you’re going to move from giving them treatment, to giving them absolutely nothing. So we tend to try to phase it in over 24 hours, if you like. Or longer." (Doctor 6)

In summary, patients could seldom express their care preferences so proxy views from families were usually sought. Families commonly reported they knew patients’ preferences. Hence family contributions to decision-making could be influential, to the extent of affecting the care that was given. Healthcare professionals reported how they communicated with families to maximise the likelihood of agreement with care decisions such as management of feeding and hydration or use of the LCP. Some care decisions were reached through negotiations between the stroke team and families and the majority of healthcare professionals described modifying aspects of care to avoid upsetting families.

Healthcare professionals often saw these negotiated outcomes as temporary, with their eventual aim being to provide end-of-life care similar to the LCP model, if not formally using the LCP itself.

Decisional responsibility

Seven relatives reported that they were not involved in decision-making. They reported that doctors and nurses had made all the decisions, occasionally in consultation with the patient. The remaining relatives (n=10) reported they had some responsibility for deciding one or more aspects of care. These decisions involved care at various points in the stroke pathway from admission to the end-of-life, from thrombolysis in the first hours post-stroke to using the LCP in later days. Examples are shown in Table 5-11 and reflect the way in which these relatives took responsibility for some decisions. Four relatives used terminology such as "signing up" (Relative 15) or "giving consent" (Relative 1) in describing their involvement in clinical decisions. Probe questions from the researcher elucidated that no documents were actually signed and the terms were used metaphorically. Only one relative reported having legal power of attorney for their family member's affairs.

Table 5-11 Frequency of relatives' reports of responsibility for clinical decisions, with supporting quotes

Clinical issue	Reported frequency (n=)	Sample quote
LCP use	3	"...so I just said, 'Look, we'll just go to Liverpool Pathway of Care and we'll just withdraw all treatment, we'll just make it palliative just now... And take the high flow oxygen away.'" (Relative 7)
Morphine use	3	"I marvelled at the fact that ... if I expressed the opinion that my mother was in pain or if [names wife] did, you'd know that they would ...give some pain relief ... almost as if we were making the decisions." (Relative 14)
DNACPR decision	2	"She was admitted to Accident and Emergency... They had to put me out sometimes to do things with her... But my mum had already written on her forms that if anything happened to her that she didn't want resuscitated. So I felt a wee bit kind of, 'Do I let them continue? Or do I highlight this? But I felt at that time, 'Ok, let's see.'" (Relative 4)
Thrombolysis	2	"I had to make a decision to give my mum ... a blood vessel bursting drug... to disperse the clot. And I had to make that decision." (Relative 17)
Place of care	1	"And yeah, everything was left to our decision... whether she would survive in the ambulance to the hospice or not, but the decision was ours." (Relative 8)
Hydration	1	"... one of my sisters ... would question us all ...She kept saying, 'Are we doing the right thing? You know, we're not giving her fluids and what if she could get better?'" (Relative 16)
Feeding	1	"... I sat one night with my wife and we talked it through and said, 'Right. We can put him on a feeding tube...' So we had a talk about it, with the rest of the family, and we pretty much decided that ... he just wouldn't be given any solids." (Relative 5)

Although ten relatives reported having some responsibility for decisions, not all were happy with their involvement. No single clinical issue emerged as especially contentious. Rather, reports of satisfaction were more related to the decision-making process than to the issue being decided. When a matrix was used (Table 5-12) to align data on satisfaction with decisions alongside data on involvement in those decisions, a pattern could be seen.

There was an apparent spectrum of satisfaction with decision-making that varied with the level of involvement participants had experienced. Illustrative quotes are shown in Table 5-12. At the centre of the spectrum, four relatives who were satisfied with decision-making also reported that their involvement had been moderately democratic and negotiated. Examples of such reports are highlighted in green in Table 5-12. At either end of the spectrum, by contrast, six relatives who expressed dissatisfaction with some aspect of decision-making also reported extremes of involvement in decisions, suggesting that

they were either under-involved or over-involved. Illustrative quotes from these participants are highlighted in red in Table 5-12. Three of the relatives who expressed discomfort with their involvement in decision-making (Relatives 1, 7 and 15) were also those who had reported the greatest dissatisfaction with care (see 5.22).

Table 5-12 Deciding clinical issues: Illustrative quotes of reported level of involvement in decision-making and associated satisfaction with decisions

Clinical issue	Involvement in decision-making	Satisfaction with decision
<i>Low involvement</i>		<i>Dissatisfied</i>
Morphine use	"Anyway, she said to me on the phone, that my sister had given consent, and I said, 'My sister isn't her next of kin. I am. It's not up to her.'" (Relative 1)	"So I phoned the consultant ... And she said, "...I've decided that she's going to go on a morphine pump." I said, "So you're just going to kill her?" So I was really quite angry at that." (Relative1)
Feeding	"The staff nurse told me, 'We're withdrawing; we're not giving her food and drink anymore.' So I agreed to that at the time ... but through the haze of it all I didn't realise they were going to actually withdraw food and drink as quickly as they did." (Relative 15)	"So we did agree verbally with the doctors that we were signing her life away; they didn't put it like that but that was basically I suppose what was happening before our eyes." (Relative15)
<i>Moderate involvement</i>		<i>Satisfied</i>
Active treatment	"The plan of care was that there would be no active life prolonging treatment. It was agreed with the medical staff and it was appropriate." (Relative 9)	[Interviewer: How involved did you feel in communicating with the staff?] "As involved as I needed to be, and my family would say the same... The most important thing was to ensure that my mother got the best care that was deliverable in the circumstances and she did." (Relative 9)
Feeding	"I think we first broached the question of this... about the nasal tube... there was a bit of a conference about that. And they thought, and we agreed, that... you can't keep putting it back in again if she pulls it out..." (Relative 14)	"They didn't go ahead and make decisions without us. There was inclusion all the way along... I think they went out their way to be inclusive, actually... I would have to say." (Relative 14)
<i>High involvement</i>		<i>Dissatisfied</i>
Withdrawal of treatment	"I just made a point of... going to speak to the charge nurse, and I said, 'Look, I want a word with the doctors and everybody.' 'Oh, yes, yes.' He knew. He knew my intentions then. I said, 'I want to just pull the plug on the treatment.'" (Relative 7)	"... I felt medically it was very poor. They'd no sense of direction; they didn't really know what they were doing with him..." (Relative 7)
Thrombolysis	"And then when the consultant on the screen [telemedicine] told me that I had to make the decision whether to give my mum this thing or not, I found that quite difficult, because I couldn't really understand. And I did say to him, 'What do you think?' And he said, if she didn't get them my mum would probably be disabled... and I said, 'Well, I'll go with what you're saying to me.'" (Relative 17)	"So that's why, initially, I <i>hated</i> that speaking to a [screen] – and I didn't like having to make that decision." (Relative 17)

Many healthcare professionals said that where patients lacked capacity the responsibility for clinical decision-making lay with the stroke team, although they would take family views about patient preferences into account. Yet three healthcare professionals felt that their approach to families regarding decisions could affect the level of responsibility perceived by families. They identified families' sense of responsibility as a misperception resulting from doctors' failure to communicate clearly:

“... There are always issues with different family members thinking different things ... and that's partly probably the way that we put things that they have difficulty because they feel like we're asking them to make decisions, which clearly, we're not. We're involving them in the decision that we believe to be appropriate, but – and obviously taking on board what they say - but I think they do sometimes struggle with that, that they're being asked to decide to withdraw treatment.” (Doctor 6)

One doctor described trying to elicit family preferences for decision-making in order to reduce the emotional burden on families:

“... With resuscitation, I don't often ask people what their family would have – sometimes they themselves say, “We don't want them resuscitated; they wouldn't have wanted to be resuscitated,” which is very useful – but I don't often kind of say it as directly as that, because I've found in the past that if you say things like that the family will feel like you're putting pressure on them to decide and think about what they would have wanted and things, so often I would have just said, I'd explain that they're very ill; would they want lots of aggressive – would they want to have everything possible or would they want to be comfortable? Kind of put it more like that.” (Doctor 8)

Nevertheless of the three relatives reporting discomfort with their high level of involvement in decisions, two (Relatives 16 and 17) felt that healthcare professionals had allowed them to direct the decision-making, leaving an enduring sense of discomfort:

“The consultant said, “Well, if you want, she can come *off* the Liverpool Care Pathway. That's always an option” ... for us as a family that was the difficult bit - which isn't really to do with the Liverpool Care Pathway - which is whether we'd made the right decision, you know... I think from a relative's point of view, being given the choice was good, because they're taking our views into – but it's hard because you then feel guilty, and think, “Well, should we put her on the Liverpool Care Pathway?” Although that's what the professionals were suggesting, we kind of got the impression if we had said, ‘Well no, we want to push for more,’ you know, you get the sort of ambivalence... we were left more confused, because they would say, you know ‘Well your mum, you don't have to stay on it. You know, she can come off it now.’ [Laugh] And we thought, ‘Oh goodness.’” (Relative 16)

Relative 16 also described wishing clinical staff would be more directive with decision-making:

“Well, if you’re asking for diamorphine it’s taking her down a different route. And I think I would have liked somebody to make that decision for us.”
(Relative 16)

By contrast, Relative 5, who was satisfied with his role in decision-making, described how healthcare professionals tactfully challenged his attempt to reverse a decision on feeding:

“Couple of times, I spoke to staff ... and I was saying, ‘Maybe I’d be better putting my father back on and feeding him through a tube.’ And they were saying, ‘Really... would it have been what he wanted?’” (Relative 5)

In summary, while some relatives and many healthcare professionals were clear that responsibility for decisions belonged to the stroke team, evidence of a more complex balance of perceived responsibility for decisions also emerged. Although most healthcare professionals reported that the role of families was only to provide information about patients’ preferences, many relatives felt responsibility for some aspects of clinical decision-making. Relatives were most satisfied with moderate involvement in decision-making, and dissatisfied with exclusion from decision-making or feeling overly responsible for decisions.

5.25 Prolonged dying

Both participant groups i.e. healthcare professionals and bereaved relatives provided their own definition of a prolonged dying process. Many healthcare professionals defined a dying process lasting beyond a week or ten days as uncomfortably prolonged. The majority reported that the LCP was typically used for between two and five days per patient. Cases where the LCP was used for more than a week or 10 days were generally regarded as unusual and protracted. Some clinical staff reported surprise when patients’ deaths were prolonged:

“... When you say the LCP it is meant to be more imminent and I think when it’s not as imminent as you’d expect you start to question, you know, “Oh, yeah, they are...” but you know yourself like there’s no reversible cause but that’s when you think, “Why are they not dying?” [*Laugh*]. Not in a – like you

do start to question it. Cause it's like they're on this, they should be, they should be going now. (Nurse 2)

Relatives articulated varied definitions of a prolonged death. Thirteen relatives reported that their family member had a prolonged death, where the LCP was used for periods of six days to two and a half weeks. By contrast, there were three reports of shorter LCP use i.e. three days to one week, that were not accompanied by comments about prolonged dying. Only one relative did not discuss time span.

Healthcare professionals reported two discrete trajectories of dying after acute stroke. While some patients died rapidly after stroke others were said to have a more prolonged dying process:

"We will either have where you're caring for that group of patients who die fairly quickly after their stroke – days – and that is set against the other group, the larger group, who die maybe within the first couple of weeks to month or so, after their stroke. So there are a couple of different groups really." (Doctor 3)

Reports of early death occurring hours or a few days after stroke typically featured dramatic presentations and large cerebral insults:

"So we do get, not infrequently, people that... have a fairly dramatic onset and dramatic presentation of stroke... Often intracerebral haemorrhages, a very big haemorrhage – general consensus would be, 'This person isn't going to survive.'" (Doctor 2)

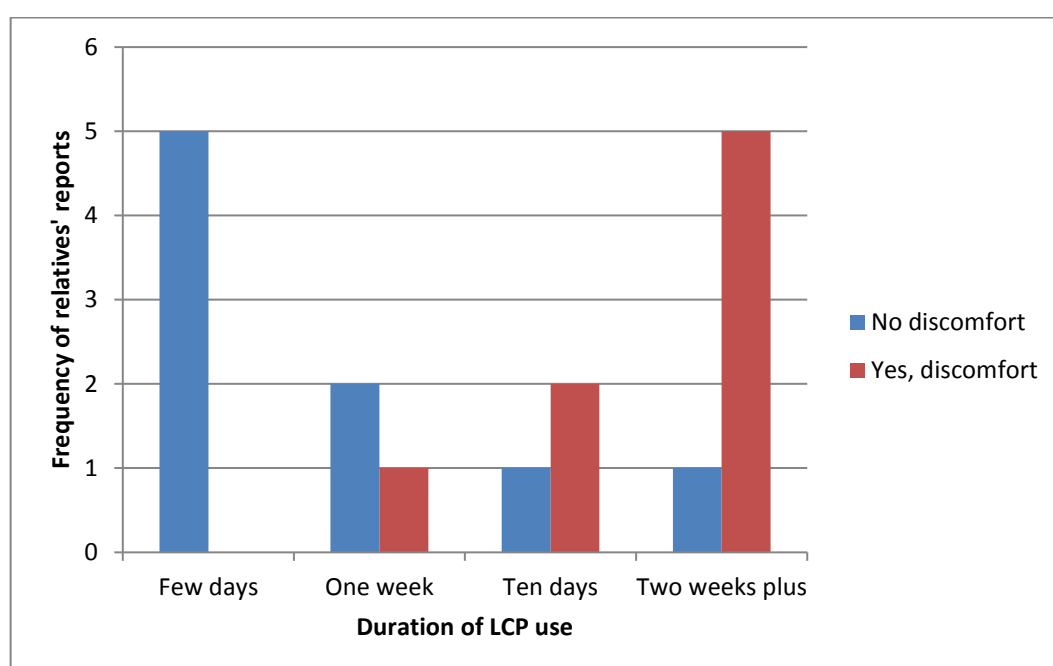
In such cases, healthcare professionals generally perceived end-of-life care management to be more straightforward. Rapid clinical deterioration often precluded LCP use but some healthcare professionals reported where possible using some principles of the LCP to manage care, such as anticipatory prescribing or withdrawal of unnecessary treatments.

Prolonged LCP use also triggered some clinicians to question whether LCP was the right management:

"And then you start to think. Question, I guess. 'Was it the right decision?' ... Almost on a daily basis ... 'If we fed them, if we did this, would it have changed...?' And we always came to the same conclusion, practically on a daily basis... 'Well, if you did this, this and this, no, it would be the same.' ... And you'd be kind of reconciled with it." (Nurse 4)

Although one relative felt a week was a long time, most did not report that LCP use lasting up to one week was distressingly protracted. Relatives showed more mixed responses to a longer dying process. Most, but not all, relatives who reported a prolonged dying process also said that it was a particularly difficult experience. As Figure 5-2 shows, the frequency of reported distress about the duration of dying increased the longer the LCP was used.

Figure 5-2 Histogram showing frequency of relatives' (n=17) reports of discomfort associated with duration of LCP use



Dysphagia and feeding decisions

Several participants suggested reasons why dying could be protracted. Three healthcare professionals suggested that prolonged dying was sometimes iatrogenic, related to continued futile interventions like antibiotics or hydration. Two nurses suggested prolonged dying could be an artefact of commencing the LCP too early, before the patient was "actually in the final stages of dying" (Nurse 4). It was also reported that patients sometimes showed clinical improvement purely because treatment was withdrawn, but such improvements were usually temporary. Finally, lack of nutrition secondary to dysphagia emerged as an important factor in prolonged dying. Reports of discomfort with

the duration of the dying process were often accompanied by reports of dysphagia and decisions to withhold or withdraw clinically assisted nutrition:

“So that was my understanding of it... ‘We’re going to withdraw artificial food, cause it’s hurting her, she doesn’t want it, she keeps pulling it out, that’s her telling us she doesn’t want it, so we’re going to take it out. If she wants food, don’t worry, we’ll give her food; she’ll not be refused it.’ So in a way it’s like starving them to death but they’ve still got the option of taking food.Basically I had to watch her over fifteen days, I had to watch her disintegrate... Because her breathing became shallower, she became thinner; I don’t know what was happening inside her. ‘Oh, she’s not in pain, she’s not in pain,’ – I don’t know how they know that – ‘Oh, she’s not in pain, she’s fine’... So in a way it’s like starving them to death ...” (Relative 15)

Healthcare professionals often reported swallowing impairments and related feeding decisions as one of the major difficulties in managing prolonged dying following acute stroke. All relatives reported their family member had swallowing difficulties after the stroke or were unconscious and therefore unable to swallow in the time between stroke and death. Nasogastric feeding was attempted for three patients, who all removed their NG tubes and refused or appeared to refuse further insertions. NG feeding was withdrawn from one patient and decisions made not to attempt NG feeding for a further three. Five patients were spoon fed small amounts orally, often by relatives, for comfort rather than sustenance. Witnessing the resultant physical decline was distressing for relatives:

"...He faded away in front of our eyes, and that was the difficult part... pretty much they’re starving to death, that’s what happened with him. My dad starved to death and that’s very very upsetting." (Relative 5)

Healthcare professionals were clear that withholding oral feeding was necessitated by dysphagia, not because the LCP was in use:

“I mean it’s not, it’s not the fact that they’re on the Liverpool Care Pathway that means they’re not getting food and drink. It’s because they can’t swallow because they’ve had a stroke.” (Doctor 6)

In all study sites, healthcare professionals addressed the discomfort of withholding oral feeding by offering what they described as “comfort feeding” where dysphagic patients would be fed small amounts orally for comfort even where there was an acknowledged risk of aspiration. Yet this type of care was reported as a difficulty by some. Speech and language therapists and a senior nurse said that some less experienced nurses were opposed

to comfort feeding because of the risks of aspiration. Two staff nurses expressed their reservations about providing such comfort food:

“Because I think I’m quite frightened of, if somebody was to choke, and then that would be a very distressing way for them to die if they choked. But yeah, we feed them. If they want fed. *[Interviewer: It sounds as if you’re maybe not very comfortable with comfort feeding]* I think it depends what and who *[light laugh]*.” (Nurse 7)

Nevertheless many healthcare professionals were clear that where dysphagic patients were clearly dying and wished food or fluids and where they would not be further distressed by aspiration pneumonia, then small amounts of oral feeding ought to be given:

“Well my views on feeding patients at the end of their life is that I would say we’ll give them comfort feeding. So if they ... a particular taste of something in their mouth they can have it; if they want sips they can have it... I think if people are at the end of their life and we are giving them comfort measures then I think totally depriving them of anything in case they choke or they aspirate is, is not what I want to be involved with. I think if patients want sips or tastes then they can have it.” (Doctor 5)

Four relatives reported feeding their family member small amounts of food for comfort. Nevertheless these reports were made in neutral terms. Providing comfort feeding to their family member did not appear to mitigate the distress for relatives of witnessing a prolonged death.

Nevertheless as shown in Figure 5-2 (p247) it was clear that not every relative reported distress in relation to prolonged dying. Therefore a matrix (Table 5-13) was used to identify any factors that might mitigate reports of distress in relation to prolonged dying. Findings from this analysis are now reported.

Managing expectations

Relatives were particularly distressed by prolonged dying when they had expected death to occur more rapidly. While some expectations seemed to be set by participants’ previous experiences and beliefs, some expectations were also apparently related to the LCP model itself:

"The problem was that she took seven days to die... *[Interviewer: What do you know about the Liverpool Care Pathway?]* It’s a pathway that’s used when individuals are recognised by a multidisciplinary team to ... be within a matter of hours or days of death.” (Relative 9)

In many cases, relatives (n=15) had been warned early in the post-stroke phase that their family member might die soon:

“About an hour later they phoned us to come in. “Your mother took another stroke, you know?” Quite a severe one like, you know... ... So we just sat in there and they confirmed ... said, “Your mother’s took a severe stroke” ... They more or less said there no recovery for this. So we sat all night. They tell you that they think she could pass away any time, like, you know. That’s what was going through my mind anyway, so we sat in there all night and went home and that was the Wednesday. It was a week on the Friday that she passed away like, you know?” (Relative 13)

Thus family expectations were sometimes shaped by the expectations and predictions of clinical staff. Clinicians often led families to expect death either early after stroke or within a week of LCP commencement. Consequently some relatives appeared unprepared for prolonged dying processes. One family asked for information without success:

“We wanted to know what the prognosis was, how long was she going to be like – we wanted to try and get some understanding, and of course they couldn’t tell us.” (Relative 10)

The eight relatives who reported particular distress with prolonged dying also reported sharing clinicians’ unfulfilled expectations of a quick death. Illustrative quotes are shown in Table 5-13. Some factors appeared to mitigate the effect of expectations. For example where relatives had previously experienced the death of a family member, where patients’ wishes were clearly accommodated or where there had been long deterioration in pre-stroke health, reports of distress from prolonged dying were less frequent. This was illustrated in the quotes from Relative 8 (Table 5-13), who had experience of hospice care and felt that a similar standard was provided in the stroke unit, and whose relative had also had longstanding serious illness pre-stroke.

Table 5-13 Prolonged dying and presence or absence of distress over prolonged dying, charted in relation to expectations

LCP duration	Did relative report dying was prolonged?	Was prolonged dying distressing?	Expectation about dying
5 days	No “... They just stopped feeding her and things, and then five days later she passed away, so it was only really five days that we knew she was dying.” (Relative 17)	No “Just glad she never suffered... She didn’t ever seem in a lot of pain; she was kept comfortable.” (Relative 17)	Not expressed
6 days (with long prior decline)	Yes “And they couldn’t have been more accommodating, more – obviously they only thought it was going to last a week <i>[laughs heartily]</i> . For it to go on six weeks, sort a thing – but they couldn’t have been better.” (Relative 8)	No “We couldn’t have asked for anything better. Cause we always, my Mum always said she didn’t really want to die in hospital, and we were getting her transferred to <i>[local hospice]</i> . My sister passed away there, and my aunt. She got the care there that she would have got in the hospice.” (Relative 8)	Staff had expectations about dying Relative’s expectations not reported
13 days	Yes “But however, nothing prepares you for the last - I would say my dad lasted about thirteen days like that - which was very painful to watch, very painful. I would say that that was the only bit that really upset me.” (Relative 5)	Yes “You know... you expect people to have a, you know, if it was a light switch and we could just switch it off, and see them peaceful, that would be nice, but that didn’t happen with my dad. And that was very upsetting.” (Relative 5)	Expectations not met
2 weeks	Yes “... We did realise the way things were being said to us, you know obviously very tactful, that ‘Right ok, my mum’s finished here. She’s not going to recover and she’s certainly not going to make it out.’ So I got the impression it would possibly only be another two or three days or a week or that, you know. It then went on I think about three weeks, didn’t it?” (Relative 3)	Yes “I just wish it would have happened sooner rather than the three weeks. Because to me it was just murder to watch my mother lying there, not being able to do anything. Can’t eat; can’t drink.” (Relative 2)	Expectations not met
2.5 weeks	Yes “That’s when they decided just to – is it the Liverpool Plan, Care Plan, you call it? – put her onto that... They thought that she would probably last maybe a week, a week and a half, and it wasn’t until – that was not quite the end of January – it wasn’t until the thirteenth of February that she actually slipped away.” (Relative 6)	Yes “But I don’t think she expected to have such a prolonged unpleasant sort of death, really. I mean you just felt that it was, I don’t know, she had no quality of life whatsoever towards the end.” (Relative 6)	Expectations not met

In addition to the staff expectations reported by relatives, three clinicians also described at interview having unmet expectations about dying. These centred on an apparent mismatch between the intended duration of the LCP and the extended time that patients took to die after stroke:

“You’ve got this in your head, ‘they’re on the LCP, they’re going to die – why are they not dying?’ ... but you know yourself there’s no reversible cause but that’s when you think, ‘Why are they not dying?’ [*Soft laugh*] ... You do start to question it. Cause it’s like, ‘They’re on this, they should be, they should be going now.’” (Nurse 2)

Four doctors described how they "managed the expectations" (Doctor 2) of families. These conversations were used to temper family expectations of aggressive treatment or to break the bad news that patients might die or survive disabled. Although they discussed general uncertainties of outcome with families, no participants reported that healthcare professionals prepared families for the possibility of a prolonged death.

In summary, managing end-of-life care was reported as more straightforward for patients who died rapidly or within the first few days after stroke. Prolonged dying was reported to be uncomfortable for healthcare professionals and particularly distressing for relatives. Much of the discomfort associated with the prolonged dying process was accompanied by reports of dysphagia, where feeding was refused by competent patients or agreed not to be in the patient’s best interest. Witnessing the slow decline towards death was difficult for families and clinicians alike. Prolonged dying prompted healthcare professionals to review their diagnosis of dying and their use of the LCP to support care. Relatives generally reported being well warned by healthcare professionals about the possibility of rapid death after stroke. Relatives who were particularly distressed by prolonged dying reported unmet expectations of early death that had usually been set by staff. Although clinicians said that managing family expectations was part of their role, families often appeared unprepared for a protracted dying process.

5.26 “Pro-active” information-giving

As reported in 5.23, families actively sought information from staff. However, written information was helpful for some families but not others. Ease of access to clinicians with specific knowledge about their family member was usually more important to relatives than receiving general information in a leaflet. Families appreciated when information was easy to access, and disliked having to search the ward for a healthcare professional with the right knowledge. Most information was exchanged face-to-face. Telephone calls were reported as being used only in emergencies, if patients had deteriorated quickly and families were being summoned urgently, or if relatives were housebound and unable to meet with clinicians at the hospital to discuss their family member’s care. Therefore the manner in which clinicians gave information to families emerged as an important issue.

From early in the analysis (5.17.6), it was clear that the geographical movement of healthcare professionals proactively towards families was relevant to the level of support perceived by those families. Families strongly appreciated being approached by staff with information, reporting this as receiving support from staff. In every site, relatives reported this spontaneous approach from staff to give information as being part of the good care they and their family member had received. This participant’s words gave rise to the *in vivo* theme name:

“The care and attention that my ma had and the way the nursing staff and the doctors, senior doctors and the consultant were with the family was really good... The nurses were out and in every couple of minutes, so it’s not as if we’d to keep going to them. 90%, well maybe 50% of the times they were in the room... But I certainly think from my recollection that it was the staff that was coming to us, they were definitely sort of proactive in telling us, ‘Look, this is what could happen now.’... I don’t think, myself, they could have done anything more, or better.” (Relative 2)

In the study sites relatives could usually see the stroke consultant by appointment. Situations where clinicians approached families spontaneously were also described. In Sites A and Sites D consultants reported at interview that they sometimes went to the stroke unit opportunistically to see relatives during visiting times. In Site C nurses also said that where their workload permitted, they undertook ‘information rounds’ with relatives at visiting time. In sites B and C, where the opportunistic contact by doctors was not reported, four relatives were dissatisfied with access to senior doctors for information and felt the nursing staff were underqualified to give accurate information. This group included the

three relatives designated by the researcher as negative cases for care quality i.e. they were dissatisfied with aspects of care quality (see 5.22). In these cases, attempts to obtain information from nurses in lieu of doctors had also proved unsatisfactory:

“I suppose it’s the same on every ward but there didn’t seem to be a doctor there an awful lot to – if we felt as if we’d any questions to ask. It was always nurses and they were kind of vague sometimes about things, because they weren’t as medically – *[Pause]* *[Interviewer: Uh huh?]* I don’t know, qualified, I suppose, as the doctors, but her care – she didn’t suffer. (Relative 17)

Nevertheless even among these negative cases, one participant was able to identify positive information-giving behaviours from some staff in the stroke unit:

“There was two young staff nurses who were absolutely lovely, who would be there when I would go in, or come in in the morning. And they would come in in the morning and sit down with me, after they had had the report and sit and tell me what had been said to them from the night staff or the day staff, whoever. Tell me what was going on... And once they had the report they would come in and speak to me and say whatever – “We’re going to do this, do that, or the other.” (Relative 1)

Seeking out information from staff was sometimes less satisfactory, as Relative 1 experienced when the two young staff nurses she described were not on duty:

“But then, when they weren’t there, when they were on days off and you would go and ask somebody else, as I say, this one wee lassie and I used to think, “Why do I bother going and asking her?” Because she would just go *[shrugs]*. What kind of answer is that for anybody? What kind of answer is that to give?” (Relative 1)

Relatives not only found it frustrating to have to seek out information. Family accounts also indicated that some relatives associated the lessening or absence of pro-active information-giving as an indicator of diminishing hope or poor prognosis:

“Early on, it was, they came to us, every time we visited. “Oh, I’ll be with you in a minute.” And I think possibly because she was very ill and they possibly didn’t expect her to live. And then when she did come round ... Gradually they weren’t quite as, they didn’t come over to us. We had to go and seek them out... You understand why people don’t have time... for you, but towards the end if we wanted to know anything we had to seek people out. Possibly because there was nothing to say to us; I mean towards the end she was just lying there.” (Relative 6)

In summary, families reported the logistical frustrations of having to seek out information. Conversely, families described spontaneous approaches from staff to impart information as supportive and consistent with good care. In two study sites, senior doctors sought relatives out to give them information, and complaints about communication were less frequent in these sites. Further, families sometimes construed a lack of pro-active information-giving as implying that nothing further could be done for their relative.

5.27 Wondering about home or hospice care

No patients were discharged from study sites for end-of-life care in another setting during the data collection period. At interview, healthcare professionals were asked about moving patients for end-of-life care. Relatives either mentioned place of care spontaneously or in response to the VOICES II survey. Twenty six participants, including ten relatives, from all sites discussed discharge to home, nursing home or hospice for end-of-life care. Home was the destination most commonly discussed. Healthcare professionals reported that discharging patients to another area for end-of-life care happened rarely, at most once or twice a year. Most described discharge for end-of-life care as a difficulty and three healthcare professionals had never seen it happen in their stroke career. Generally healthcare professionals wouldn't raise the subject with patients or families and no relatives reported patients being offered the option of receiving end-of-life care at home. Seven healthcare professionals stated it was a subject about which families seldom or never asked. One nurse suggested that coping with the rapid trajectory of stroke might deter some relatives from asking about discharge home for end-of-life care:

“I think when you work in a hospital you forget how intimidating it is, you know; lots of different things in hospitals are *[laugh]* really intimidating and you know, they'd maybe be scared to say... especially because they're a bit shell-shocked anyway, with the situation...” (Nurse 9)

Nevertheless four relatives reported that although they had not considered it at the time, they had wondered about the issue since their bereavement:

"I've wondered why was she not sent to a hospice. To die. If there was nothing the hospital could do. Did they feel that it was too much of an upheaval for her? It was a question I never really asked, but I thought about it since."
(Relative 6)

A further four said they had asked to take the patient home or to a nursing home for end-of-life care but the doctors were against discharge because they judged the patient too ill to be moved or the burden of care too great for families to manage. Healthcare professionals generally reported they would consider discharge for end-of-life care where the patient had requested it, where there was a clear network of family support at home and where family and staff were in agreement. The practicalities of managing care at home would be discussed with the requesting families, using discussions either to manage family expectations seen as unrealistic or to clarify discharge plans. Healthcare professionals said that such conversations often led to families dropping their requests. This was confirmed by interview data from relatives. Three of the four relatives who reported asking to take their family member home withdrew their request after discussion with the stroke team and were satisfied with that outcome:

“But one of my wishes was that we could get him back to the care home but that wasn’t possible... However we were always led by Dr [*names consultant*] and when I spoke to her she said that unfortunately that wouldn’t be possible because the journey would probably kill him. So although they were aware of mine and the rest of the family’s wishes, they couldn’t comply with them because medically, they stepped in, which is fine. It wasn’t a demand from us; it was just a wish that we could get him back to the care home. It didn’t become a great big issue.”(Relative 5)

The remaining relative (Relative 1) expressed anger over not being allowed to take the patient home. Relative 1 was one of the three relatives in the study who thought care was poor:

"So anyway, this wee young doctor, this wee resident came down to speak to me, and she said she [*the patient*] wasn’t doing very well, and I said, “I can see that. I think I’m just going to take her home.” “Well,” she said, “I can’t allow you to do that.” And I said, “Why not?” And she said, “Because she had a cardiac episode last night”... I feel she would have been better looked after here... And I would have been happier if she’d been here at home. She probably would have died but I’d have known she was here with her own family." (Relative 1)

Specific clinical aspects of stroke were identified as major barriers to discharging patients home to die. Time issues were the most crucial, with rapidly declining stroke trajectories precluding discharge. Discharge for end-of-life care was more likely to happen, healthcare professionals said, where there was more time for planning and co-ordination:

" I mean you would raise it if it was somebody who just purely had some suppressed conscious level and couldn't eat and you know, you had a feeling it might be a week or you know, longer, before they died. You might do it in that setting. But in the more acute people, unfortunately by the time you can organise it, it'll probably be too late." (Doctor 6)

Additionally, healthcare professionals were clear that dying stroke patients required a level of care that was difficult to deliver at home. Clinical issues such as swallowing difficulties, immobility and reduced conscious level were better managed in hospital:

"I think we probably tend to just accept it as a given that we don't really have many choices. I may be under-estimating the level of community support for these people but I mean, I have arranged that kind of alternative for people with other end-of-life conditions but it's, they're usually different, the people are not usually as incredibly disabled [*gentle laugh*] as I'm thinking in my kind of stroke scenario." (Doctor 1)

Discharging patients for end-of-life care at home was reported to be a "logistical nightmare" (Doctor 6), requiring negotiation with multiple agencies such as social work or primary care services. Negotiations could be also complicated by a rapid stroke trajectory that necessitated care to be organised at short notice. Healthcare professionals said that these logistical difficulties were a reason not to raise the subject of care at home with families:

[Interviewer: Is it something you would ask families about? Preferred place of care?] Probably not. Just because I know about the logistics of it. I think if I worked in a cancer unit, absolutely, and if it was, well, almost predicted, and they could get things in. I think because ours happen sudden and... [*Voice trails off*] (Nurse 7)

Healthcare professionals drew distinctions between providing end-of-life care at home for stroke patients and for those with other conditions, particularly those with more straightforward trajectories and organised services such as cancer:

"I think, again it's just anecdotal, but I would say it's a minority of relatives that ask that compared to other illnesses, would be my experience. I would say in my non-stroke work that's a much more frequently asked question, 'Can we take him home?'" (Doctor 3)

In summary, discharging patients home or to another setting for end-of-life care was a rare occurrence and did not happen during the data collection period of the study. Healthcare professionals said that relatives did not ask about discharge, yet a small number of relatives had actually asked and a further small number had considered the issue in the months after

their bereavement. Requests for discharge tended to be negotiated between the stroke team and families with the outcome that families withdrew the request. Some clinicians reported stroke-related and logistical difficulties in arranging for stroke patients to receive end-of-life care at home. Further, clinicians reported a contrast between the infrastructures for end-of-life care at home after stroke and in other clinical conditions, particularly cancer.

5.28 Answering the research questions: thematic data

The themes which emerged from the qualitative interview data clearly related to the research questions on family and health-care workers perceptions of using an end-of-life care pathway, the clinical decision to use such a pathway and the experience of pathway use for families and the multidisciplinary team. Data relating to preferred place of care were also generated.

In respect of the research question on care perceptions, interview data showed that providing end-of-life care after acute stroke was often difficult. Stroke-related challenges such as rapid onset, uncertain outcome, and feeding difficulties affected many aspects of end-of-life decision-making and care. Yet care supported by the LCP was generally perceived as good, particularly where families felt they were well-supported by healthcare professionals in terms of communication and practical needs. Specific reports of the LCP were less prominent than reports of stroke-related issues.

In relation to question 2a i.e. the clinical decision to use the LCP, interview data showed the decision to use the LCP was an unhurried linear process of multiple steps that commonly involved families. Healthcare professionals drew on a range of judgements and consulted with the wider team in recognising when patients were dying. Weekend working patterns sometimes hampered decisions to use the LCP. Few patients could speak for themselves therefore family views of patient preferences could influence care decisions, to the point of altering usual care. Many relatives felt responsible for some aspect of clinical decision-making but only those who were either excluded from decision-making or felt overly involved reported enduring discomfort.

With regard to question 2b on experiences of LCP use, interview data showed that dying processes perceived as prolonged were distressing for both healthcare professionals and

relatives, particularly in relation to feeding issues. Families were generally well-prepared for the early death of their relative but not for an extended dying process. Families were particularly distressed by prolonged dying when their expectations about timing were not met. Families were active in asking for, organising and giving care as well as sourcing information for themselves. Families reported that pro-active information-giving by healthcare professionals was especially supportive, and some interpreted decreased or absent information-giving by staff as a poor prognostic indicator. A minority of families reported that written information about end-of-life care was useful.

Research question 3 i.e. outcomes for LCP patients discharged or transferred for end-of-life care in another care setting could not be answered by the casenote review because no patients were discharged (see 4.15). Interview data suggested an explanation for the absence of discharges. Healthcare professionals seldom raised with families the possibility of discharging patients home or to another care setting for end-of-life care because they felt the stroke-related challenges were too great or the primary care infrastructure was insufficient. Some staff reported it was a topic about which families never asked, yet several families did raise the issue with the stroke teams. For a few relatives, questions about place of care endured months after the death of their family member.

Having presented the qualitative interview findings, the findings from the VOICES II survey are now presented, before this chapter concludes with a list of key points.

5.29 VOICES II findings

Seventeen bereaved relatives (100%) completed the VOICES II survey after their semistructured interview. The researcher completed a separate form for each participant, including the two interviews involving family dyads. The VOICES II tool was straightforward to complete apart from the item on pain from section F, 'Care Received in the Last Three Days of Life'. Some participants struggled to answer the question because their family member had received morphine for distress which may or may not have been related to pain. The presence of aphasia and obtundation made it difficult for onlookers to tell, as this quote shows:

[Interviewer: The next question is, 'Do you think her pain distressed or bothered her – yes, no, don't know?'] She was deeply comatose. I don't think so. *[Interviewer: Ok. Don't think so. Is that 'Don't know' or 'No'?]* Don't know. *[Laughs]* *[Interviewer: Did she have any treatment for her pain?]* Yes. *[Interviewer: And did that relieve her pain?]* Yes. *[Interviewer: Completely or partially?]* *[Long pause]...* *[Interviewer: Or 'Don't know'?]* Distress. It relieved completely. Whether or not the distress was caused by pain, I don't know. *[Interviewer: Ok. So would you say, 'Don't know'?]* I don't know if the distress was caused by pain but the treatment relieved the distress. *[Interviewer: Ok. I'll put 'Don't know'. Are you happy with that?]* It's your questionnaire. *[Smiles and laughs]*. (Relative 9)

Findings are presented for each section of the VOICES II survey that was used.

5.29.1 Care during last hospital admission

Responses in this section related to care received throughout the whole admission, from accident and emergency departments and medical receiving units up to and including acute stroke units.

Almost all (n=16, 94.1%) relatives felt hospital was the right place for their family member to be cared for, although three (17.6%) said they had experienced problems in having their relative admitted. The majority (n=15, 88.2%) had been able to discuss their relative's condition and any anxieties about their relative with staff. Almost all (n=16, 94.1%) felt there were usually enough nurses on duty to provide care. Views were more mixed regarding the knowledge base of doctors and nurses caring for the stroke patient, with ten (58.8%) reporting that all staff knew enough about their family member's condition, five (29.4%) believing that most staff knew enough and two respondents (11.8%) feeling only some doctors and nurses knew enough.

Patients were always treated with dignity and respect by staff according to 11 (64.7%) respondents while almost one third (n=6, 35.3%) reported this happened most or some of the time. Eleven relatives (64.7%) were involved as much as they wanted with decisions about their family member's treatment and care, while two (11.8%) said no decisions were required. Three relatives (17.6%) would like to have been more involved while one said they would have preferred less involvement. Most relatives (n=14, 82.4%) said no decisions were made about treatment or care which their family member would not have

wanted, two (11.8%) said that decisions were made that their relatives would not have wished for and one was unsure.

Care received during the hospital admission from nurses was rated as excellent more frequently than care received from doctors (see Table 5-14), although overall differences were small.

Table 5-14 Responses to VOICES II questions “Overall, do you feel that care from doctors/nurses in the hospital was...” [17 respondents]

Care rating	Doctors n (%)	Nurses n (%)
Excellent	10 (58.8)	13 (76.5)
Good	4 (23.5)	2 (11.8)
Fair	2 (11.8)	1 (5.9)
Poor	1 (5.9)	1 (5.9)
Total	17	17

5.29.2 Care received in the last three days of life

In contrast to the previous section, all participants’ responses to this section of the VOICES II survey related to stroke unit care.

Most relatives (n=15, 88.2%) felt that the personal care needs of their family member were met and that there was sufficient nursing care provided at all times. There were some discrepancies in reports regarding the need for decisions to be made. Twelve (70.6%) relatives reported they were involved in decision-making as much as they wanted, two (11.8%) would have preferred more involvement and three (17.6%) said no decisions were needed. Yet while most relatives (n=15, 88.2%) said no decisions were made which the patient would not have wished, in a small change from the previous item, two said no decisions were needed. Again, while 14 relatives (82.4%) said no decisions were made against their own wishes, two (11.8%) said decisions had contravened their wishes while this time one relative said no decisions were needed. Most respondents (n=16, 94.1%) said it had seemed likely their relative would die, with ten (58.8%) reporting their relative was unconscious all the time, and the remainder reporting their relative was unconscious or drowsy most of the time.

Difficulties in answering items on pain were highlighted in 5.28. Responses to questions about pain were conflicting and these are now reported. Twelve respondents (70.6%) said their relative had suffered no pain, three (17.6%) reported their relative had some pain of which two said the pain distressed the patient. A further two relatives (11.8%) did not know if their family member experienced pain. In answer to the item, “Did he/she have any treatment for her pain?” 11 respondents (64.7%) said their relative received treatment for pain and five (29.4%) said their relative did not have any pain while one did not know. Eight respondents (47.1%) agreed that treatment had relieved their relative’s pain completely, one (5.9%) said treatment helped some of the time, six respondents (35.3%) said their relative had no pain and two (11.8%) did not know the answer.

One respondent (5.9%) said their relative had received tube feeding in the last three days of life and felt this was in the patient’s best interests. Thirteen respondents (76.5%) said their relatives did not receive clinically assisted nutrition in the last three days and this was in their relatives’ best interests. A further two were unsure if withholding feeding had been in their relatives’ interests and one respondent said it was not in their relative’s best interests that feeding had been withheld.

All respondents said their relative was treated with dignity and respect all or most of the time in their final three days. Twelve (70.6%) said care in the last three days was excellent, four (23.5%) said it was good and one (5.9%) said it was fair.

5.29.3 Circumstances surrounding the death

Most respondents (n=15, 88.2%) felt their relative had died in the right place although two respondents (11.8%) said hospital was not where their relative had wanted to die. Eight respondents (47.1 %) were present at the death and nine (52.9%) were told their relative would die soon. When their relative was dying 11 (64.7%) respondents either didn’t know or only partly knew what to expect. Most respondents (n=14, 82.4%) felt their relative’s religious and spiritual beliefs were considered by staff.

Following their bereavement few respondents (n=3, 17.6%) had discussed their experiences with any health or social care professional or bereavement service. Of those, two had spoken to their GP and one to a mental health nurse caring for another relative.

Nine participants (52.9%) were content not to speak to anyone, two would have liked to and three were unsure. Six respondents (35.3%) identified help that they would have liked to receive post-bereavement. Two respondents from Site B (11.8%) wanted “someone to talk to”, another two wished support with returning equipment used by the deceased to primary care services and one wished more practical information about registering the death. One participant in Site D said they would have liked LCP related follow-up to confirm they “made the right choice” for their relative. Although bereavement follow-up was available in Site D (5.13.1) it had not been offered to this relative.

5.30 Answering the research questions: VOICES II data

In respect of the second research question on care perceptions, most respondents were satisfied with the care their relative had received. The care provided by nurses was rated as excellent more frequently than the care provided by doctors.

With regard to question 2a on decision-making, over half of relatives said they were satisfied with their level of involvement in decision-making throughout the whole hospital admission. Responses that no decisions were required in the final three days appeared inconsistent.

In relation to question 2b on experiences of LCP use, some respondents struggled to answer the questions on pain management accurately and again, responses appeared inconsistent. Most respondents were satisfied that withholding feeding had been in their relative’s best interest although a small number were unsure or dissatisfied. A majority of respondent were unsure what to expect when their relative was dying. A third of respondents expressed unmet needs for practical and emotional post-bereavement support.

With reference to the third research question on place of care, most respondents were satisfied with the care their relative had received and with the fact that their relative died in hospital.

5.31 Key points for the discussion chapter

Interview data collection for this study was undertaken against a context of intense media scrutiny of the study topic. In the stroke units studied, infrastructure limitations sometimes hampered end-of-life care provision. Most staff had been taught how to use the LCP, although education systems commonly depended on information cascade, rendering them vulnerable to staff turnover and attrition. Formal sources of support were available to staff although most commonly, staff sought informal peer support within their teams.

The following points were also identified:

- Healthcare professionals described a range of clinical judgements used in consultation with the wider team to recognise when patients were dying
- Participants reported a clear process for deciding to use the LCP, in which families were commonly involved
- Weekend working patterns were sometimes identified as barriers to LCP-related decision-making
- LCP-based care was generally reported to be of good quality
- Families were reported as able to strongly influence some end-of-life care decisions, including the decision to use the LCP
- Some relatives described an enduring sense of primary responsibility for crucial care decisions
- Relatives reported most satisfaction with moderate involvement in decision-making
- Families often reported that healthcare professionals prepared them to expect their relative's death early after stroke. However, families often appeared unprepared for a protracted dying process, particularly where patients had persistent dysphagia
- Proactive information-sharing by healthcare professionals was perceived by families as being emotionally supportive

- Healthcare professionals were reluctant to initiate discussions about preferences for place of care, yet families considered the issue during the care episode and after their relative's death
- Bereaved relatives described unmet needs for practical and emotional post-bereavement support.

In the next chapter, the interview findings are integrated with findings from the casenote review and both are discussed in relation to existing literature.

Chapter 6 – Discussion

6.1 Introduction

This mixed methods study using casenote review, qualitative interviews and a questionnaire was undertaken to investigate clinical decision-making leading to use of an end-of-life care pathway i.e. the Liverpool Care Pathway (LCP) for patients dying in acute stroke units. The study also explored patient, family and healthcare professional experiences and outcomes associated with LCP use.

When the study began, the LCP was recommended by the four UK home nation governments (see 2.8.2) as a tool for supporting good quality end-of-life care. This study was conducted during a period of intense media scrutiny of the LCP, although Scottish Government policy expressed continued support for the LCP until several months after the study was completed (see 2.15.2). Since the LCP was withdrawn from use in the UK in 2013-14, this study represents a unique opportunity, that is now unavailable, to explore LCP use in Scottish acute stroke units.

The three research questions were:

1. Are patients with fatal stroke who are judged to require an end-of-life care pathway different (in terms of age, gender, stroke type/severity or comorbidity) from patients with fatal stroke who die without introduction of an end-of-life care pathway?
2. What are family and health-care workers perceptions of using an end-of-life care pathway for patients who die after acute stroke?
 - 2a. How is the clinical decision made to place a stroke patient on an end-of-life care pathway?
 - 2b. What is the experience of end-of-life care pathway use for stroke patients, families and the multidisciplinary team?
3. What is the outcome for stroke patients on an end-of-life care pathway transferred from stroke unit to another care facility?

In this chapter, the study context is considered. Thereafter findings from the casenote review and the interviews are integrated for discussion. Findings are considered with respect to the research questions, under the relevant headings and are evaluated in relation to literature reviewed in Chapter Two. The study's contribution to knowledge is stated before methodological issues are discussed and the rigour and trustworthiness of the findings are assessed. Thereafter the researcher's influence on the study and the study limitations are considered.

6.2 Education and clinical infrastructure

Almost two thirds of healthcare professionals interviewed had received LCP education that was routinely available in their hospitals (Table 5-7). No participating healthcare professionals reported a lack of knowledge relating to LCP use in their units, healthcare professionals described LCP-based care and decision-making clearly (5.22, 5.24) and there were few complaints about LCP use itself (5.22). Thus it could be argued that LCP education was apparently effective. Yet for many healthcare professionals, LCP training was their only source of post-registration education about end-of-life or palliative care (Table 5-7). Additionally, in some areas staff turnover was a barrier to the cascade system of knowledge transfer (5.19.2.3). Now that the LCP has been withdrawn in the UK, substitute sources of post-registration training in end-of-life care remain an important issue.

Regardless of whether the LCP was used or not, healthcare professionals reported that inadequate overnight family accommodation, a lack of single rooms and insufficient private spaces for sensitive conversations sometimes made end-of-life care provision particularly difficult (5.19.2.2). Lack of side rooms to nurse dying patients has been reported before (Healthcare Commission, 2007, 2008) as has the lack of private space for discussions with families (Di Leo et al., 2011; O'Hara, 2011; Clark et al., 2012). Nevertheless relatives tended to report appreciatively how staff had addressed infrastructure challenges (5.22). Although the infrastructure limitations were felt keenly by some healthcare professionals, families often viewed staff efforts to mitigate the shortcomings of stroke unit accommodation e.g. by offering easy chairs, pillows or blankets, as examples of good care (5.22).

6.3 Answering the research questions

The first research question was answered fully by the casenote review (4.15). The second research question and sub-questions were answered fully by the interview data (5.28), the questionnaire (5.30) and some casenote review data (4.15). The third question could not be answered by the casenote review because no relevant casenotes were identified (4.11). The interview data offered an understanding of the issue and this is discussed in 6.3.5. In the following sections, study findings are summarised and then discussed in relation to key literature.

6.3.1 Clinical and demographic differences between LCP and non-LCP groups

The casenote review showed no significant demographic or clinical differences between patients whose care was supported by the LCP and those whose care was not (4.12). Although by univariate analysis age seemed a statistically significant factor in decision-making (4.12.2), when included in a multivariate analysis with other variables such as stroke type, stroke severity and comorbidity, age was not a significant predictor of LCP use (4.12.3). Thus the study identified no casenote evidence that decisions to use the LCP were related to patient demographics such as age, sex or comorbidity.

It is possible that if the study were repeated with a larger sample, statistically significant differences might be found. Nevertheless, whether such findings would be clinically significant is uncertain because the qualitative interview findings supported the casenote data i.e. clinicians did not cite age as a consideration in recognising dying or deciding to use the LCP (5.24). These findings stand in contrast to reports (Doughty, 2012b; Pullicino, 2012) of the LCP being used to target the elderly or the very sick. Both casenote and interview data showed that decisions to use the LCP were based on factors other than clinical demographics and these are considered in 6.3.3.

The first research question was answered fully. Patients with fatal stroke who were judged to require the LCP were not different (in terms of age, gender, stroke type/severity or comorbidity) from patients with fatal stroke who died without introduction of the LCP.

6.3.2 Family and healthcare professional perceptions of using an end-of-life care pathway

Data from qualitative interviews and the VOICES II survey tool showed that relatives reported LCP-based care as being of good quality (5.22, 5.29). It must be noted that contemporaneous data on care satisfaction were not collected from non-LCP families, so comparisons cannot be made. Healthcare professionals also reported that the LCP was helpful in clinical practice (5.22).

In relation to the literature, care was rated as excellent or good much more frequently by proxies in this study (94.2%, see 5.29.2) than by proxies in the survey of London stroke unit care (56.8%, see 2.10.3) reported by Young et al. (2009). However, although both studies used the same VOICES II tool, the sample in this study was too small to draw conclusions regarding differences between the studies. Additionally it is not known whether end-of-life care pathways were used in the stroke units reported by Young et al. (2009), hence conclusions regarding differences in reported care quality cannot be reached.

The LCP itself was not prominent in families' accounts (5.20). Rather, stroke-related issues such as the emotional burden of proxy decision-making (5.24) and the distress of witnessing an apparently prolonged death tended to feature (5.25), as did the general kindness and caring approach of the stroke team (5.22). Two of the three relatives who expressed negative views about communication and decision-making also reported good quality physical care (5.22).

Although healthcare professionals reported positively about the LCP (5.22), it must be stressed that these participants self-selected for the study. Negative perspectives from non-participants may have been missed. This point is discussed as a study limitation in 6.8.2

Thus the second research question was answered. This research question also had two sub-questions and these are now discussed separately. First, LCP-related decision-making is discussed (6.3.3) and thereafter the experience of LCP-based stroke care is considered (6.3.4).

6.3.3 The clinical decision to use the LCP

Interview data showed that the decision to use the LCP was a consultative, unhurried and linear process, in which families were commonly involved (5.24). Interviews and casenote data showed that healthcare professionals used a range of clinical judgements and consultation with the wider team to recognise when patients were dying (5.24, 4.13). Casenote data showed that decisions to use the LCP were typically made within normal weekday hours i.e. in the late morning or mid-to-late afternoon, and decisions at night were rare (Figure 4-2). Weekend working patterns were sometimes described in interviews as barriers to LCP-related decision-making (5.24), and this was confirmed by casenote data that in some sites showed weekday patterns in decisions to commence the LCP (4.13.3.2). Interview data (5.24) also indicated that families were able to strongly influence some end-of-life care decisions, including the decision to use the LCP. Some relatives retained an enduring sense of primary responsibility for crucial care decisions (5.24). Relatives reported most satisfaction with moderate involvement in decision-making (Table 5-12).

In relation to the literature, although patient, family and healthcare professional experiences of the LCP have been studied (see 2.11 and 2.12), decision-making processes culminating in LCP use have not been reported before, either in general acute hospital settings or in stroke care settings. Therefore the model of the decision-making process (Figure 5-1) identified in this study contributes new knowledge on the topic. The process was inclusive, allowing sufficient time to address stroke-related uncertainties and to gather views of patient preferences.

Recognising dying

Recognising dying was the first step in deciding to use the LCP. Like the stroke professionals studied by Burton and Payne (2012) and Gardiner et al. (2013), participants in this study reported that recognising dying after acute stroke was sometimes difficult (5.21, 5.24). Nevertheless, healthcare professionals in this study knew how to identify dying and clearly described ways of addressing the diagnostic difficulties (5.24). At interview, healthcare professionals reported taking account of altered breathing, deteriorating vital signs, imaging results, clinical trajectory and intuition to judge if patients were dying (5.24). Thus the clinical indicators of imminent dying reported in this study are similar to those of altered respiration, conscious levels and vital signs already reported by Bloomer, Endacott, O'Connor, & Cross (2013) and Domeisen Benedetti et al.

(2013) as used by healthcare professionals in cancer and non-cancer settings (2.9). Additionally healthcare professionals in this study used stroke severity, imaging results and the views of multidisciplinary team colleagues to counterbalance clinical uncertainty, to assist the judgement of reversibility and thus to gauge whether LCP might be appropriate (5.24).

Healthcare professionals in three study sites used the LCP four point checklist (version 11, see Appendix 1) intended to help recognise dying (Table 4-1). While others have reported that using the LCP helps staff to recognise imminent dying (Clark et al., 2012) and to act on that recognition (Thurston and Waterworth, 2012), healthcare professionals in this study expressed a different view, with some criticising the LCP checklist (5.24). Like the healthcare professionals studied by Domeisen et al. (2011), some healthcare professionals in this study reported that the checklist created difficulties in recognising dying after stroke, because its criteria were so similar to the clinical features of severe acute, yet non-fatal, stroke. This was typified in Nurse 2's statement, "I think a lot of our well stroke patients could fit the criteria for the LCP." Healthcare professionals voiced concerns about using the LCP model, developed in cancer care where trajectories were said to be more certain, in acute stroke care with its inherent uncertainties and challenges. It was notable that in the site where version 12 i.e. no checklist was used, there were no reported concerns with fitting the model. However, the clinicians studied by Clark et al. (2012) and Thurston & Waterworth (2012) worked in acute medical and surgical wards rather than acute stroke units and hence may have had different experiences of the LCP checklist from the stroke healthcare professionals in this study.

Thus this study adds knowledge as to how healthcare professionals address the complexities of recognising dying after acute stroke. Healthcare professionals in this study worked beyond the scope of the LCP checklist, using a considered blend of general and stroke-specific clinical indicators and intuition, checked against the views of colleagues, when concluding that patients were dying. Hence in contrast with clinicians studied by Di Leo et al. (2015) healthcare professionals in this study used patient-focused clinical judgement and consultation rather than a tick-box approach to recognising dying and deciding LCP use.

It is also noteworthy that relatives reported making their own judgements about dying without receiving explicit pointers from staff, noting clinical trajectory and breathing changes and linked their observations with previous experiences (5.24). Eychmüller et al. (2013) call for recognition of dying to include the observations of family carers. Although healthcare professionals in this study said they consulted one another to confirm their judgements about dying, they did not report including relatives in that aspect of consultation.

Deciding to use the LCP – barriers and facilitators

Healthcare professionals' reported reluctance to implement the LCP out-of-hours (5.24) can be seen as logical. Crucial elements of the normal decision-making process were absent, namely: sufficient familiarity with the patient as to enable recognition of dying; opportunities to consult with colleagues including seniors and relatives. These findings supplement those of Freemantle & Seymour (2012) and Pollock, Caswell, Porock and Harwood (2013), who reported that LCP decision-making was more challenging out-of-hours for cancer patients and elderly patients, respectively. Further, although Freemantle and Seymour (2012) reported that weekend working patterns or rapid patient deterioration sometimes barred LCP use, their study was in cancer care. This study shows that the barriers of weekend working patterns or rapid patient deterioration also pertained, at times, in stroke care. This study also showed the added obstacle of family opposition to LCP use, which participating healthcare professionals said was increased by negative media coverage about the LCP (see 5.19.2.1).

Healthcare professionals described how they addressed barriers to LCP use (5.24). Their strategies included using the principles of LCP-based care to provide what they considered good quality end-of-life care, but without actually using formal LCP documentation (5.24). Using the principles without the paperwork tended to be temporary, with the aim of working towards LCP implementation after the weekend or when families felt able to accept formal LCP use. Additionally, healthcare professionals used the strategy of "holding off" (5.24, Figure 5-1) to allow sufficient time for discussion and resolution with families. Healthcare professionals were clear that where families vetoed the LCP or related care, the care which was actually given was agreed with families. Thus family wishes were not disregarded but worked with. These findings therefore supplement those of Gardiner,

Harrison, Ryan and Jones (2013) who identified barriers to using an end-of-life pathway in stroke units but did not describe strategies used by clinicians to address such barriers.

Clinicians described an additional strategy for addressing the weekend barrier to LCP use i.e. documenting contingency care plans (5.24) e.g. Dr 2's statement, "We try and make sure that there's handover to the people that are coming on." Communicating plans in advance has been reported before (O'Hara, 2011) (see 2.14.3). In this study, although a few clinicians described creating such plans ahead of weekends, reports were infrequent. Even though the LCP is now withdrawn in the UK, communicating ahead regarding end-of-life care plans at weekends and out-of-hours will still be required. Hence research investigating the effectiveness of weekend contingency planning for end-of-life care is indicated.

Decisional responsibility

It was clear that dying stroke patients seldom decided their care. Casenote data showed that on admission fewer than half of patients could talk and fewer than one fifth were orientated to time and person (Table 4-4). Hence for around 80% of patients, discussion of preferences, even at an early stage, would have been impossible. These data corroborated and contextualised the interview data, where many families reported acting as proxies for their relative (5.24).

Families were also active participants in care (5.23). Relatives requested, organised and negotiated care, and in some cases delivered hands-on care, specifically oral and eye care. This is consistent with the findings of Glaser & Strauss (1966) who reported that some relatives in their study took on a "worker" (p165) role. This study highlights the active role played by families in end-of-life stroke care. Casenote data showed that families were commonly involved in discussions about their relative's end-of-life care (4.14.6). Recorded rates of discussions with families about the decision to use the LCP (4.14.6) were higher in this study (81.3%) than the 71% reported for England (2.10.2) by the Marie Curie Palliative Care Institute Liverpool and the Royal College of Physicians (2011). The higher rate of discussions with families in this study may reflect the high rate of communication impairment in this stroke patient population (Table 4-4). The nature of LCP-related discussions has not been reported before. Therefore this study adds descriptive data on the involvement and role of families in end-of-life decision-making after stroke.

Healthcare professional reports in this study generally reflected UK guidance (General Medical Council, 2010) i.e. that clinicians made decisions and families had an advisory rather than executive role (5.24). Nevertheless interview accounts indicated that families sometimes demonstrated social agency (see 2.10.1) of the type described by Hewson (2010), where their influence in decision-making could be powerful (5.24). Other studies have also reported the influence of relatives on end-of-life decision-making. For example nurses in Italy negotiated with relatives over clinical decisions to withdraw treatment or administer morphine (Di Leo et al., 2011). Nurses in that study described relatives as meddlesome (see 2.10.2), whereas healthcare professionals in this Scottish study reported families' attempts to influence care as arising from discomfort or lack of readiness to accept the impending death (5.24), and discussed how the stroke team addressed that discomfort. As reported in Norwegian care homes (Dreyer, Førde and Nortvedt, 2010), healthcare professionals in this study too could be pressured by families into departing from normative practice to accommodate strong family opinions or avoid distress for relatives (5.24).

Therefore this study adds to Dreyer et al. (2010) by showing that practice variations in response to family pressure also occur in acute hospital stroke care and include decisions to use or not use an end-of-life care pathway. This study also identified that differentiations from normative practice tended to be of limited duration and were used to meet usual care goals but by alternative routes or over longer time spans or in smaller stages.

Overall, VOICES II survey data and interview data showed that, like the LCP relatives surveyed in the Netherlands by Veerbeek et al. (2008), many relatives in this study were satisfied with their involvement in end-of-life decision-making (5.29.2, 5.24). Nevertheless, some were dissatisfied with decision-making if they perceived too much responsibility for decisions or if they were excluded from decision-making (5.24). These findings are consistent with those of Young et al. (2009) who found that relatives who were involved as much as they wanted with decision-making were most satisfied with end-of-life stroke care (2.10.3).

The long-term discomfort with decisional responsibility reported in this study (5.24) is similar to that identified among bereaved relatives in Norway (Dreyer, Førde and Nortvedt, 2009), in Wendler and Rid's (2011) systematic review (see 2.10.2) and in the Netherlands

(de Boer et al., 2015) (see 2.10.3). Although some of these studies included stroke patients, none reported whether an end-of-life care pathway was involved. This study therefore adds to knowledge by showing that unwanted perceptions of responsibility experienced by bereaved relatives extended to the decision to use an end-of-life care pathway.

Decision-making with patient proxies (i.e. relatives) and clinicians generally fitted the shared model that Edwards & Elwyn (2006) reported between patients and doctors in Welsh general practice (see 2.10.1). Relatives and clinicians in this study exchanged information about clinical issues and patient preferences (5.24). Relatives usually reported either that thereafter the stroke team had made all the clinical decisions or relatives comfortably took personal responsibility for clinical decisions (5.24). These findings are consistent with those of Edwards & Elwyn (2006) who identified that even where medical consultations involved decision-making that was shared, some patients asserted they were solely responsible for the resulting clinical decision, perceiving decisional responsibility that was not objectively demonstrated in consultations (see 2.10.1). Nevertheless, in this study interview data from healthcare professionals indicated that at times families could indeed influence some clinical decisions (5.24).

Notwithstanding, some of the bereaved relatives studied by de Boer et al. (2015) preferred doctors to make decisions unilaterally (see 2.10.3). In this study a similar wish was reflected in the statement from Relative 16, “I think I would have liked somebody to make that decision for us.” Some relatives in this study were uncomfortable with their perceived responsibility for decisions (5.24). Although several doctors said they routinely elicited families’ preferences for decision-making the approach was not universal among the healthcare professionals interviewed (5.24). Edwards & Elwyn (2006) suggested that at least some dissatisfaction with shared decision-making arose from an unmet wish for paternalism, and these findings support that view. Further, the findings highlight the need for clinicians to elicit and follow proxies’ preferences for decision-making, and make clear to proxies that their role is advisory.

Summary

Thus the second research sub-question regarding the nature of clinical decision-making at the end of life after stroke was fully answered by this study. The normal process for deciding to use the LCP was identified, and strategies used by clinical staff to overcome

difficulties were elicited. Family roles and experiences in relation to end-of-life decision-making after stroke were described. The implications of these findings for clinical practice are stated in Chapter Seven.

6.3.4 The experience of end-of-life care pathway use for stroke patients, families and the multidisciplinary team

Casenote data showed that although the median duration of LCP use was two days, it was used for longer than three days for a third of patients and in eight cases the LCP was used for one or more weeks (4.13.3.3). Healthcare professionals and relatives defined LCP use lasting more than around a week as a prolonged death (5.25). Prolonged dying processes, particularly in association with severe dysphagia, were especially distressing for families (5.25). Healthcare professionals often prepared families for the rapid death of their relative but families often appeared unprepared for a prolonged dying process (5.25). Written information about the LCP and end-of-life care was helpful only for some families, but sharing spoken information proactively was described by families as being emotionally supportive (5.26). Referrals to specialist palliative services occurred rarely (4.12, 5.21). Relatives expressed unmet needs for practical and emotional support after bereavement (5.29.3).

In this section, these findings are discussed in relation to literature reviewed in Chapter Two.

Trajectories of dying

The median duration of LCP use was marginally longer than the 31 hour average (see 2.5) in England (Marie Curie Palliative Care Institute Liverpool and Royal College of Physicians, 2011) for patients dying from non-cancer causes including stroke (4.13.3.3). The 0-23 day range for LCP duration in the casenote review was also longer than the range of 0-17 days reported in Adams et al.'s (2013) retrospective audit of a LCP use in a UK acute stroke unit (see 2.9.3). Inferences cannot be drawn from these differences because Marie Curie Palliative Care Institute Liverpool and Royal College of Physicians (2011) did not provide data on range, and there are no data on the patient population or type of stroke unit reported by Adams et al. (2013).

Glaser and Strauss (1968) identified that staff became familiar with the dying trajectories that they saw most frequently (see 2.8.6). Interview data from this study suggest that healthcare professionals were similarly aware of common temporal patterns of dying in their stroke units (5.25). The early and late trajectories identified by healthcare professionals in this study (5.25) resemble the quick deaths and lingering deaths reported by Glaser and Strauss (1968). This finding supports Small & Gott's (2012) contention that for patients dying in acute hospitals, dying trajectories may still resemble some described by Glaser and Strauss.

The interview data in this study suggested that using the LCP, developed in a cancer setting where short rapid trajectories were common, set expectations for at least some healthcare professionals that patients would die within hours or days, rather than the weeks that sometimes transpired (5.25). Some staff using the LCP found it difficult to adjust to another dying trajectory. This was illustrated by Nurse 2's words, "They're on the LCP ... why are they not dying?" ...They should be going now" (5.25). Glaser and Strauss (1968) reported that staff not only organised their work to suit the dying trajectory most common in their clinical area, but they also questioned when their expectations about trajectories were unmet (2.8.6). Similarly staff in this study also questioned when LCP patients took longer than expected to die (5.25).

This study also indicates that some patients and families had the power, or social agency, to potentially modify dying trajectories (see 5.24). Patients and families could influence clinical decisions, for example by refusing feeding or requesting continued hydration, potentially lengthening or shortening the duration of the dying process. This supports Small & Gott's (2012) argument that the ability of individuals to exert influence on clinical decision-making should be considered in relation to dying trajectories (2.8.6).

Witnessing and managing prolonged dying

Findings from this study are consistent with those of Rogers & Addington-Hall (2005) i.e. that for healthcare professionals, managing prolonged dying after stroke is more difficult than managing care for patients who die rapidly (2.10.3). However, Rogers & Addington-Hall's (2005) design was qualitative and did not report interviews with relatives. Therefore this mixed methods study adds quantitative detail to substantiate concepts of dying

trajectories in acute stroke and incorporates the perspectives of family members. Further, in contrast to Rogers & Addington-Hall (2005) where no end-of-life care pathway was used, this study investigated prolonged dying in an acute stroke unit where the LCP was used.

Rogers & Addington-Hall (2005) identified that managing dysphagia was particularly difficult in prolonged dying, raising tension between clinicians and families. Similarly, dysphagia emerged as an uncomfortable issue in this study (5.25) but for different reasons. In Rogers & Addington-Hall (2005) all patients surviving beyond seven days received some form of clinically assisted nutrition, and this could engender tensions between staff and families, with families more reluctant than staff to commence feeding. By contrast, in the study reported here many patients who had prolonged deaths did not receive clinically assisted nutrition because it was judged not to be in their best interest or was refused by patients who remained competent for some time (5.25). Nevertheless, withholding or withdrawing feeding was uncomfortable for healthcare professionals and families alike.

Casenote data showed no significant difference in enteral feeding patterns between LCP and non-LCP patients (4.14.3) in the study sites. However, the number of patients receiving enteral feeding was small and a larger sample might show a different pattern. Nevertheless as Relative 5 said, families found it difficult that their relative “starved to death” (5.25). The use of the LCP did not preclude or eliminate the distress associated with dysphagia and prolonged dying after acute stroke. Yet the VOICES II data indicated that although prolonged dysphagia was distressing, most relatives were satisfied that withholding feeding had been in their family member’s best interests (5.29.2).

Relatives’ reports of decisional responsibility (5.24) indicate a different experience for the families in this study from the families studied by Rogers & Addington-Hall (2005) and Blacquiere, Gubitz, Dupere, McLeod, & Phillips (2009) where decisional conflict regarding feeding was reported (2.10.3). Yet from the data reported here it is not possible to conclude causality i.e. whether such differences arose because using the LCP prompted more open discussions with families or whether practice in the Scottish stroke units differed from that previously reported in other countries.

Managing expectations and awareness contexts

Family distress over the duration of dying was linked to unmet expectations of timing, some of which were set by clinicians (see 5.25). Families were often warned by healthcare professionals early in the hospital admission that their relative might die very soon. Yet none reported being told that their family member might die a lingering death, although at least some healthcare professionals were aware that prolonged death was possible (5.25). This is consistent with the theory of mixed awareness contexts (see 2.8.6) originally described by Glaser and Strauss (1966), because there was generally open awareness in relation to the possibility of sudden death but not of possible prolonged dying. Although at interview some healthcare professionals acknowledged prolonged trajectories were possible, none reported warning families of the possibility.

Small and Gott (2012) identified reluctance on the part of healthcare professionals to discuss the timing and likely mode of death with heart failure patients and their families, with the consequence that healthcare professionals operated in a closed awareness context, where they knew likely outcomes but patients and families did not (2.8.6). Healthcare professionals in this study were also operating in a closed awareness context regarding the possibility of prolonged deaths. At least some acknowledged that prolonged death was possible, yet did not disclose the possibility to families. The reminders in the LCP documentation for healthcare professionals to discuss the diagnosis of dying and the plan for care with patients and families (see Appendix 1) did not ensure candid disclosure of all eventualities.

At least one family in this study clearly asked healthcare professionals about the likely duration of dying (5.25) i.e. these relatives wished to operate in a context of open awareness. This was exemplified by Relative 10's words, "We wanted to know what the prognosis was, how long was she going to be like ...and of course they couldn't tell us." This is consistent with the findings of Richards et al. (2013) who reported that while some patients and families preferred not to know about prognosis, others wanted full disclosure from healthcare professionals (see 2.8.6). However, in this study the relatives' desire for open awareness was not met.

The finding that some healthcare professionals in this study were operating in a closed awareness context regarding prolonged dying aligns with evidence that some healthcare

professionals find conversations about dying to be uncomfortable (2.8.7), even where the LCP is used (Walker and Read, 2010; Freemantle and Seymour, 2012). Healthcare professionals in this study showed some discomfort during interviews when discussing aspects of prolonged dying. Some nurses expressed professional disquiet about providing comfort feeding in case patients choked (5.25). One doctor appeared to show social discomfort when describing conversations held directly with competent patients about withdrawing treatment (5.21). For healthcare professionals, prolonged dying processes usually involved making difficult decisions to withhold or withdraw treatment, including clinically assisted nutrition or hydration (5.21). Hence healthcare professionals may have been reluctant to discuss the issue with families because it held areas of emotional, social and professional discomfort.

Yet Payne, Burton, Addington-Hall and Jones (2010) report that relatives of dying stroke patients want health professionals to be honest about uncertainty and possible prognosis, and welcome opportunities for discussion. The findings from this study suggest that future models of end-of-life care in acute stroke should include communicating eventualities clearly to families in advance, including the possibility of a prolonged dying process.

Pro-active information-giving

Families showed information-seeking behaviours similar to those demonstrated by stroke patients' relatives in the study reported by Wallengren, Segesten and Friberg (2010), using the internet and informal social networks to source information and not universally finding written information helpful (5.23). As with participants reported by Payne et al. (2010), families in this study valued the interpersonal dynamics of their interactions with the health professionals who gave them information (5.26). In this study, the fact of contact was at times appreciated more than the content or importance of the information shared (5.26).

This study highlights that the literal movement of staff towards patients and families was positively perceived, in that families particularly appreciated spontaneous approaches from staff bringing information (5.26). Therefore this study may augment the findings of Payne et al. (2010) in clarifying that not only was the interaction between families and staff important, but also the instigation of that interaction was relevant. Relatives in this study perceived spontaneous approaches as being socially or emotionally supportive (5.26). This

finding is consistent with Meeker and Jezewski's (2005) recommendation that healthcare professionals take a proactive approach to end-of-life communication with patients and families (2.14.4). Conversely, families interpreted diminishing or absent pro-active information-giving as having negative prognostic significance and as a reason for losing hope (5.26).

It is unclear whether the pro-active information-giving reported in this study occurred because it was an ongoing action indicated for staff by the LCP documentation (see Appendix 1) or if it was routine practice in the stroke units studied. Regardless of the reason for this type of care, the intervention was generally appreciated by families. A possible explanation for this family satisfaction might be that pro-active information-giving fitted with the active approach to information-giving identified by Forster et al. (2012) as improving patient satisfaction (2.14.4). Although Forster et al.'s (2012) Cochrane review considered information-giving relating to rehabilitation rather than end-of-life care, and carer satisfaction did not reach statistical significance in the studies they reviewed, findings from this study indicate that some families looking for end-of-life stroke information also value an active approach to information-giving.

Specialist palliative care referrals

Although it is recommended that stroke patients have access to specialist palliative services for managing symptoms or decisions (NHS Quality Improvement Scotland and University of Glasgow, 2010; Intercollegiate Stroke Working Party, 2012a; Holloway et al., 2014) such referrals were rare in this study (4.12, 5.21). Although aware of referral mechanisms and the type support available from palliative care services, stroke healthcare professionals usually handled challenges in end-of-life care without specialist support (5.21). Although reported rates of referrals to specialist palliative services from acute stroke units vary widely internationally (2.14.2) these findings are consistent with findings from the UK study by Payne et al. (2010) where no stroke referrals to specialist palliative services were made, and with those of Jeffries, Shipman and Wee (2012) whose interviews with UK stroke professionals showed they rarely sought specialist help for dying patients.

Nevertheless healthcare professionals, patients and families in this study might have benefited from specialist palliative service support. Healthcare professionals described

difficulties in recognising dying or making feeding decisions (5.21), and questioned their own clinical judgement in cases where patients took longer than expected to die (5.25). These issues fit the complex end-of-life needs identified by Audit Scotland (2008) as requiring input from both generalist and specialist palliative services. Although healthcare professionals in this study reported that specialist palliative services could support them with complex issues (5.21), they tended not to ask for such help. Reasons for this are unclear but could relate to the strong sense of teamwork reported by healthcare professionals, where uncertainties were addressed (5.24) and support sought primarily within the multidisciplinary stroke team (5.19.2.4).

Care after death

One study site (Site D) provided bereavement support (see 5.13.1) that exceeded the LCP's requirements for care after death (see Appendix 1) and which met the recommendations of Holloway et al. (2014) i.e. that patient proxies bereaved by stroke be given access to bereavement support (2.8.3). In Site D, several months after the bereavement, relatives were invited to a meeting in the stroke unit where they could ask questions about the care episode. Hence, although care after death was often poorly documented (4.14.8), the casenotes did not reflect all aspects of bereavement care.

VOICES II freetext data identified suggestions for improving bereavement support which could be used clinically (5.29.3). Some participants wanted practical information about returning the decedent's medical equipment, and appointment systems at local government departments to smooth the death registration process. A small number of relatives wished opportunities to discuss and reflect on the care episode.

Summary

Thus the second research sub-question regarding experiences of LCP-based care for patients, families and healthcare professionals was answered. Distinct trajectories of dying in the aftermath of acute stroke were identified, and the challenges of witnessing and managing prolonged dying were described. The possible influence of the LCP model in setting expectations was suggested and role of healthcare professionals in setting

expectations for the duration of dying was explored. Pro-active information-giving was identified as a positive source of emotional support for families. Low rates of referrals to specialist palliative were highlighted, and elements of good practice in supporting bereaved relatives were reported. The implications of these findings for clinical practice, policy and research are stated in Chapter Seven.

6.3.5 Outcome for stroke patients on an end-of-life care pathway transferred from a stroke unit to another care facility

As casenote review showed, no patients were discharged for end-of-life care in another setting during the data collection period (4.11). Nevertheless the issue of discharging dying patients to other care settings was discussed in interviews (5.27) and possible reasons for the lack of discharges emerged. Healthcare professionals were reluctant to initiate conversations about preferences for place of care, stating that families seldom raised the subject, or that patients were too sick to be moved to other care settings or expressing concerns about inadequate resources to provide end-of-life care at home. Some families did raise the topic but were content, after discussion, for their relative to remain in the stroke unit. Others wondered about the issue months later, at interview. Thus the interview data offered an explanation of the casenote review findings.

In relation to the literature, the lack of patients discharged to receive end-of-life care in other settings is similar to previous UK studies (2.13). For example Payne et al. (2010) reported no stroke patients were offered discharge for end-of-life care at home and Coombs et al. (2014) identified that dying patients were seldom transferred home from ICU. Patients in stroke and ICU areas share some common characteristics such as rapid onset of severe life-threatening illness, impaired cognition or inability to communicate and these may complicate efforts to establish patient preferences. Yet in this study, as in Payne et al. (2010) and Coombs et al. (2014), preferences for place of care were seldom discussed. These findings stand in contrast to UK guidance which states that dying stroke patients should have the opportunity for rapid discharge home (or to a hospice or care home) and that decisions should take account of preferences (Intercollegiate Stroke Working Party, 2012a).

As with participants in Gott et al., (2011) and Coombs et al. (2014), healthcare professionals in this study reported that uncertainty about the timing of dying impeded

discharge home for end-of-life care. Further, other barriers to discharge described in this study resembled those reported in ICU settings by Coombs et al. (2014). Illness severity, logistics of the transfer and insufficient community resources were cited in both studies. These barriers seem to militate against UK policy which at the time of the study was to reduce numbers of hospital deaths and facilitate dying at home where preferred by patients (Department of Health, 2008; The Scottish Government, 2008; All Wales Palliative Care Planning Group, 2008; Department of Health Social Services and Public Safety, 2010). This study could uncover no evidence regarding the reported barriers because no discharged patients were available for follow-up. This study's findings therefore support the recommendation of Coombs, Long-Sutehall, Darlington and Richardson (2014) that further investigation of the topic would be useful. Additionally, although several healthcare professionals indicated that discharge home for end-of-life care was more achievable for cancer patients than for stroke patients, this study did not generate data to support or refute the apparent double standard.

Healthcare professionals seldom raised the topic of discharging dying patients and said families tended not to ask about it (5.27). Yet almost half of relatives in this study said they either asked about discharge at the time or thought about it after bereavement. The lack of discussion contrasts with Government recommendations in England and Scotland at the time which directed that advance care planning should be used to elicit patients' preferences regarding their place of care (Department of Health, 2008; The Scottish Government, 2008). Further, where families did raise the issue it was usually agreed after discussion that the patient should remain in hospital (5.27). VOICES II data indicated that all but two relatives were satisfied with their family member's place of death (5.29.3), suggesting that even if preferences could not be accommodated families appreciated the chance for discussion. For relatives who did not discuss it at the time the issue remained an enduring question.

In summary, the third research question was not answered directly because no patients were discharged for end-of-life care in another setting. Pertinent explanatory data were collected in interviews. This study contributes new knowledge by identifying the barriers that stroke healthcare professionals believed prevented discharge for end-of-life care in non-ASU settings. Implications for clinical practice and further research are stated in Chapter Seven.

6.4 Contribution to knowledge

This study answered the research questions and contributes to existing knowledge. It was the first and only to investigate LCP use in Scottish stroke care, and first in the UK using mixed methods to explore LCP use.

The study adds to knowledge about the LCP and end-of-life stroke care, summarised as follows:

- Decisions to use the LCP were not related to clinical characteristics such as age, stroke severity or comorbidity.
- Healthcare professionals addressed the challenge of recognising dying after stroke by involving the wider clinical team in synthesising multiple factors, including physiological measurements, stroke severity and clinical trajectory.
- The decision to use the LCP was inclusive, considered, unhurried and linear in nature.
- Weekend working patterns sometimes created difficulties in deciding end-of-life care in stroke units.
- Relatives held considerable influence over the decision to use the LCP and other aspects of end-of-life stroke care.
- Relatives experienced enduring discomfort if they perceived excessive responsibility for decisions or if excluded against their wishes from decision-making. Shared decision-making appeared to reduce the impact of perceived responsibility.
- Relatives were not prepared for prolonged dying processes after stroke, which were reported as particularly distressing and often associated with severe dysphagia.
- Pro-active information-giving by staff was perceived as supportive by relatives.

- Healthcare professionals were reluctant to discuss preferences for place of care with families because of perceived logistical and infrastructure difficulties.

More broadly, this study indicates that in acute stroke care, LCP-based care was generally perceived as good quality by relatives and healthcare professionals. This is consistent with some of the examples of good practice described in the Neuberger et al. (2013) review of the LCP in the UK (2.15.1). This study did not find convincing evidence to support the withdrawal of the LCP from clinical practice.

6.5 Methodological issues

Several methodological issues merit discussion and are considered in the following section. First, interviewing as a data collection method is reviewed. The reliability of casenote data and use of the VOICES II tool are also discussed. Finally, the extent to which grounded theory was produced and the integration of mixed methods in this study are appraised.

6.5.1 Alternative data collection methods

The data which were collected using interviews and the VOICES II survey did not meet Silverman's 'Dead Researcher' test for the primacy of data i.e. data that were generated free from the researcher's influence (see 3.10.2.1). On the contrary, the researcher was involved in generating those data. Instead, useful primary data that were less influenced by the researcher could have been collected by using direct observation of decision-making. However, issues of ethics and sensitivity precluded that approach (see 3.10.2.1). Further, using interviews and surveys yielded data on participants' perceptions and experiences which might have been difficult to capture using direct observation. Despite Silverman's (2013) argument, the interviews in this study afforded rich and complex data on shared decision-making and prolonged dying. Additionally, interview findings on end-of-life decision-making from this study are consistent with findings from studies using direct observation such as Rogers and Addington-Hall (2005).

6.5.2 Reliability of casenote data

Although casenote data met Silverman's 'Dead Researcher' test of being free from researcher influence at least until the point of data collection, there was still an issue of reliability. According to Andrews and St Aubyn (2015) care that is documented in clinical records is considered evidence that care was given, and hence casenote records are a defence against legal claims to the contrary. Therefore the researcher approached casenote data with the view repeated by Andrews and St Aubyn (2015) that if care was not recorded in the casenotes then there was no evidence that the care had actually been given.

Yet it is possible that records could have been inaccurate, as poor record keeping has been reported by the Nursing and Midwifery Council (2012) as one of the top five reasons in UK nursing for misconduct referrals to the regulatory body. Care recorded as being given might not have been, and care not recorded in casenotes could have been given in fact. This may be particularly relevant to the recorded rates of conversations about end-of-life care and spiritual needs which were lower than rates of anticipatory prescribing, particularly in the non-LCP casenote group. It is possible that conversations did take place but were not recorded, perhaps because standard ward documentation did not prompt staff to make such a record. A similar effect may have applied to all casenotes in relation to poorer recording of care after death. Further, documentation that leaflets were not given could reflect scarcity of leaflets rather than a failure to give them to families. Using an alternative data collection method such as direct observation of care might have avoided this issue, yet there were good reasons not to use this method (see 6.5.1).

6.5.3 Using the VOICES II tool

Using the VOICES II tool was of modest benefit in this study yet its use highlighted an important issue for using the tool in future stroke studies. The sample of relatives answering the survey was small and consequently inferential statistical analysis was not possible. This outcome was unanticipated because the final sample size could not be known in advance and there was scope in the ethics application for the sample to have been larger (up to 60 participants). Hence the decision to use the VOICES II was reasonable but in the event the survey produced limited findings.

Further, some participants struggled to complete the items on pain relief (see 5.29) apparently because of confusion about pain assessment and management. Relatives' reports about analgesia administration highlighted the challenges of pain assessment, illustrated by Relative 9's statement (5.29) regarding morphine, "I don't know if the distress was caused by pain but the treatment relieved the distress." According to NHS Quality Improvement Scotland and University of Glasgow (2011) pain assessment in acute stroke can be difficult because of patients' sensory, cognitive and communication deficits, yet the stroke-specific VOICES II tool did not accommodate such difficulty.

This inflexibility of the tool became apparent because the survey was completed face-to-face with participants. It is noteworthy that although the original tool was validated for postal or face-to-face administration (Addington-Hall et al., 1998) piloting was not reported for the subsequent stroke-specific version (Young, Rogers and Addington-Hall, 2008; Hunt et al., 2011). Consequently studies administering the stroke-specific versions of VOICES II by post (Young, Rogers and Addington-Hall, 2008; Young et al., 2009) may have failed to detect the issue. Further, piloting in this study did not indicate a problem (see 5.10.2), perhaps because the pilot participants did not have experience of stroke pain assessment or management. Hence this study highlights a difficulty with the stroke-specific version of VOICES II in relation to pain management in stroke and the tool may require modification.

Nevertheless its use did allow outline comparisons (6.3.2; 6.3.3, p274) with findings from other studies that also used VOICES II (Veerbeek et al., 2008a; Young et al., 2009). Further, using the tool sometimes prompted participants to share experiences that were not elicited by the main interview guide.

6.5.4 The use of grounded theory

This study did not seek to establish formal generalisable sociological theory as defined by Glaser and Strauss (1968a). However, the researcher used methods recognised by Bryant and Charmaz (2007) as consistent with a grounded theory approach (see 3.10.1). These included concurrent data collection and analysis, coding and categorising data, analysis by constant comparison, inductive and abductive analysis, hierarchical coding processes,

theoretical and purposive sampling, theoretical sensitivity, theoretical saturation, writing memos and producing theory.

Using these methods enabled a theoretical understanding of the data. Hence grounded theory was produced in the sense of constructivist grounded theory suggested by Charmaz (2013) i.e. that processes and social actions within the data were interpreted and understood within their context. Nevertheless although the understanding of the data is situated i.e. related only to the study setting, some aspects may apply more widely in stroke care and transferability of findings beyond their context is considered in 6.6.2. Some findings offer wider understanding of end-of-life stroke care and yield useful suggestions for practice, which according to Strauss and Corbin (1998) are both key aspects of grounded theories.

6.5.5 Using and integrating mixed methods

This study was strengthened by the use of mixed methods, enabling a richer understanding of end-of-life stroke care than previous single method studies in the area such as Rogers and Addington-Hall (2005), Young et al. (2009), Mazzocato et al. (2010) and Payne et al. (2010). Hence this study was able to explore decision-making and patient and family experiences in greater detail than previous studies. The qualitative and quantitative approaches worked synergistically at various stages in the study, confirming the choice of a convergent design with equal weighting. For example during data collection, data about weekend care that emerged from qualitative interviews triggered a sub-analysis of quantitative casenote data, uncovering decision-making patterns throughout the working week (4.13.3). Also, informal conversations in study sites (5.14, p192) about using LCP principles triggered the researcher to explore in interviews how healthcare professionals addressed barriers to LCP use. Further, as demonstrated throughout previous sections in this chapter, the qualitative and quantitative findings combined to enrich the interpretation of findings. Thus findings from the two paradigms not only showed convergent validity as described by Sandelowski (2000) but also showed benefits of mixed methods described by Bryman (2012) in enhancing each other while enabling multiple research questions to be answered.

6.6 Rigour and trustworthiness

The study was strengthened by various measures adopted to enhance rigour and trustworthiness and these are now considered.

6.6.1 Quantitative data

Casenote review

The planned measures to ensure rigour in the casenote review were implemented. Using a standardised data extraction tool incorporating valid, reliable measures such as the Charlson Comorbidity Index and the Six Simple Variables items (3.9.4, 3.11.1) enhanced internal validity and objectivity. The use of a single data collector increased the reliability of data collection. Further, the risk of sampling bias was reduced by using consecutive sampling and ensuring casenotes were identified by a third party i.e. the clinical team, not the researcher.

VOICES II questionnaire

Using a pre-designed, standardised tool to measure care satisfaction strengthened reliability and heightened objectivity because there was less scope for the researcher to influence or vary the questions asked. Reliability was also enhanced because the questionnaire was administered face-to-face by one researcher. Nevertheless difficulties emerged related to a lack of piloting and these are discussed in 6.5.3.

6.6.2 Qualitative data

The extent to which the study achieved key aspects of trustworthiness suggested by Lincoln and Guba (1985) is now considered. These aspects are credibility, transferability, dependability and confirmability. In this thesis the researcher has made every attempt to lay out the nature and flow of the research in order to provide an audit trail and ensure trustworthiness.

Credibility

According to Holloway and Wheeler (2010) a credible study accurately represents the social realities of participants. Measures to ensure credibility were implemented as planned. The data collection period for the whole study lasted 15 months and for the qualitative component 11 months, hence engagement in the field was prolonged and a large volume of data generated (Table 5-8). The researcher triangulated between data sources by using multiple hospital sites and by including healthcare professionals and relatives. Negative cases were considered, enhancing understanding of issues such as decisional responsibility. Coding and analysis were reviewed by an academic supervisor, the stakeholder group and a managed clinical network group (5.17.6, 5.17.12) who confirmed the relevance of the analysis to clinical practice. Mindful of literature (Barbour, 2001) on burdening participants, the researcher did not return transcripts to bereaved relatives, in an effort to minimise distress. Instead intra-interview member checking was used and stakeholder group views on the emerging analysis were sought (5.17.12). Although a maximally varied sample of relatives may not have been achieved in terms of relationships to decedents (see 6.8), the sample was socioeconomically varied and the healthcare professional sample showed variation in discipline, age and experience.

Transferability

Holloway and Wheeler (2010) define transferability as the extent to which study findings apply to other settings and Hannes (2011) suggests that consumers of research can judge transferability if sufficiently thick description is provided of the original sample, setting, researcher and participant characteristics, and methods. To that end, background information on study sites (see 4.1) and participant demographics (see 5.18.1 and 5.19.2) are provided, and analytical methods reported clearly in Chapters Four and Five.

Dependability

According to Graneheim and Lundman (2004) evidence of consistent data handling and consistent analytic decisions throughout a study enhances its dependability. Such evidence was achieved in this study by keeping a clear audit trail of methods and decisions in the form of a coding journal and field notes. Excerpts from field notes are shown in 5.15.5 and 5.19.2.1 and an excerpt from the coding journal in 5.17.9. Hannes (2011) suggest that consistency with data handling is also enhanced by peer review of coding. Hence this measure was used as reported in 5.17.6.

Confirmability

Confirmability refers to the degree of neutrality achieved by the researcher (Holloway and Wheeler, 2010) and Reason (1988) suggests that while researcher influence on a study cannot be eliminated it may be mitigated through reflexive articulation i.e. making bias explicit. In this study confirmability was enhanced by using a coding journal, coding memos and reflective memos to record decisions and review the researcher's experiences and viewpoint. An excerpt from a coding memo and its role in stimulating the researcher's analytical reflexivity is reported in 5.17.10. Further, reflective memos were used after personal bereavements experienced by the researcher. Peer review of coding, stakeholder group involvement and ongoing discussion of the study and its analysis with academic supervisors also mitigated the researcher's influence on the study, enhancing confirmability.

6.6.3 Ethical aspects of study conduct

The advice obtained from the UK-wide consultation (see 3.12.2) with stakeholders in bereavement care held true. They advised that relatives who did not want to participate could decline, relatives might find participation beneficial, and making contact within three to six months of bereavement was acceptable.

Three relatives did contact the researcher to decline participation, explaining that they found talking about their experiences upsetting. Further, consistent with the findings of Pleschberger et al. (2011), beneficence was reported by some relatives who said the interview was their first opportunity to discuss their experiences, and that they welcomed the chance to tell their story. No participants commented on the time lapse since their bereavement, leading the researcher to assume that it was acceptable.

The strategy for supporting distressed participants and thereby enhancing non-maleficence appeared successful. No relatives wished to have a third party present for support, although in two cases additional family members joined the study, gave consent and became participants. Breaks were offered when relatives became distressed during interviews but were declined. No participants were distressed at the end of interviews and escalation of the strategy was never required.

Using gatekeepers avoided implied coercion of potentially vulnerable individuals and therefore enhanced respect for participants' autonomy. However, the strategy may have affected recruitment among relatives and this is discussed as a study limitation in 6.8.

Measures used to support the researcher reduced the emotional burden and physical risks associated with conducting the study. These measures included training in handling difficult interviews, supervision by experienced researchers and using the university's lone worker policy.

6.7 Reflections on the research process

Several issues relating to the research process emerged during the study and were often captured in the field notes (see 5.15.5). These issues are now discussed.

6.7.1.1 Researcher's perspective

Bryman (2008) suggested that if researchers are familiar with participants' experiences or work settings this may help them understand the context and content of what participants' stories. In this study, the researcher was familiar with the context of health care in Scottish hospitals through clinical experience, and also had personal experience of bereavement including that caused by stroke. Hence the researcher had some understanding of the perspectives of both the healthcare professionals and relatives who participated in the study. Notwithstanding, the researcher was not specialised in stroke care and had no experience of an end-of-life care pathway being used for a relative, so any prior understanding was limited.

6.7.1.2 Researcher interview training and skill

The researcher had previous research experience of casenote review and qualitative interviewing (5.11).

Concerns about role conflict have been reported (Johnson and Clarke, 2003) by nurses researchers struggling to balance an observational research role with their professional

caring identity, particularly when interviewing distressed participants. For the nurse researcher in this study, the interview training (University of Oxford, 2015) undertaken was helpful, and enhanced the researcher's previous experience. It afforded practice in handling distressing interviews and helped the researcher to put aside the concept of the neutral interviewer, accepting their influence on interviews.

Taylor (2005) recommended that researchers reflect on their role and influence in interviewing. In this study the researcher became more comfortable with allowing silence as the study progressed. This probably reflected an increased confidence in interviewing skills. In each interview the researcher attempted to follow the participant's direction initially, becoming directive later to ensure all topics on the interview schedule were covered. Directive actions were similar to those listed by Taylor (2005) e.g. returning to statements made earlier in the interview or raising a new subject. Again, the researcher increased in skill and familiarity with the topic guide as the study progressed.

6.7.1.3 Researcher-participant relationship

Participants knew that the researcher was a nurse studying for a PhD. Some asked the researcher clinical questions or for information about health services. The researcher attempted to answer honestly. Other participants expressed opinions about care quality and these are presented in 5.22. Answering questions and sharing information may have helped maintain an even power balance between interviewer and participants. The researcher's influence appeared consistent with the experience of Sque (2000) who reported that having a nursing and research background helped establish trust with participants, and equipped the researcher with communication and support skills.

Nevertheless in this study the researcher's professional background may have influenced the views participants were willing to express. Of the three bereaved relatives expressing strong dissatisfaction with care two were nurses, one practising and one retired. Both spoke of shared knowledge with the interviewer. This is consistent with the findings of Richards & Emslie (2000) whose middle class interviewees tended to assume parity and shared insider knowledge with the GP researcher (see 3.10.2.9). In a further similarity to Richards & Emslie (2000) where interview participants apologised to the GP researcher for

criticising doctors, some participants in this study described unsatisfactory incidents but hastily made clear that they were not complaining about care. Therefore it is possible that participants' knowledge of the researcher's background may have increased the willingness of some to criticise care while limiting criticism from others.

6.8 Study limitations

6.8.1 Casenote review

The external validity of the casenote review was limited by its small sample size and non-probability sampling. Further, the sample did not represent the true population of all patients dying after acute stroke, because it omitted stroke patients who died in emergency departments or medical receiving wards, and may also have missed ASU patients who died following transfer to other wards. Additionally it is possible that with a larger dataset, age might have shown as a statistically significant predictor of LCP use. Yet the interview data suggest that might not be a clinically relevant finding as age was not reported by interview participants as a factor in decision-making. Further, the sample was generally similar by age and sex to a broader Scottish sample of stroke deaths from a comparable time period (Information Services Division Scotland, 2012) and was drawn from a sample of consecutive deaths across a mix of hospital sites. Hence the sample is likely to be reasonably representative of deaths following acute stroke in Scotland.

The researcher was aware of the potential for a Hawthorne effect (Polit and Beck, 2008) i.e. an increase in activity caused by the presence of researchers. A Hawthorne effect on rates of LCP use may have been counterbalanced by the adverse media coverage during the study, reported by healthcare professionals in interviews as inhibiting their use of the pathway, particularly later in the study.

6.8.2 Interviews

The transferability of findings from this study is enhanced by the thick description of the sample and settings provided in 4.1, 5.18.1 and 5.19.2. Nevertheless, the following limitations to generalisability apply to sampling:

- There may have been selection bias in recruiting the interview sample for both relatives and healthcare professional participants. First, bereaved relatives were identified by stroke unit staff. As described in 5.9, not all relatives who fitted the inclusion criteria were asked either because staff weren't aware of the study, were too busy, forgot or felt it was inappropriate to ask. Thus the sample may have been biased by excluding families who seemed very distressed. Also, staff may have avoided asking relatives where communication was difficult for other reasons e.g. complaints pending, anger or aggression issues. Further, staff may have selected the 'best' relatives or those most likely to give positive feedback.
- More than two thirds of healthcare professionals did not respond to interview invitations (see Table 5-5). Those who responded were generally enthusiastic about the LCP with some acting as LCP 'champions' in their units. Health care assistants were included on the recommendation of charge nurses who may have selected staff supportive of the LCP. Thus it is possible that only healthcare professionals enthusiastic about the LCP participated, and that the study missed negative healthcare professional opinions on the subject. Therefore the views of those healthcare professionals and bereaved relatives who chose not to participate remain unknown and this is a potential source of bias.
- Purposive and theoretical sampling were hampered by time and funding limits (see 5.6.5 and 5.8) with the effect that this study omitted patients with very short dying trajectories after stroke. These issues could be addressed in future studies by widening the type of sites for sampling and allowing longer time periods for recruitment, although such a measure might require increased funding. Notwithstanding, the absence of data on rapid dying does not diminish the relevance of findings regarding prolonged dying. Reports of rapid death after severe stroke occurring in A&E departments and medical receiving units that triggered early end-of-life decision-making could not be confirmed by this study and the issue requires further research.
- Although the healthcare professional participants were varied in terms of discipline, experience and seniority, other aspects of the interview sample were less varied and this may limit transferability. All interview participants belonged to one UK

geographical area and the relatives' sample was relatively homogenous as the participants were mainly the adult children of stroke patients. Nevertheless, the study data reflected varied models of stroke service configuration, enhancing transferability. Further, the health boards sampled vary widely in terms of socio-economic status, and the relatives participating came from a varied range of postcodes.

Although patient representatives were involved in the Best Practice Statement project from which this study partly arose (see 1.1), there was no patient or public involvement in the design or analysis of this study. In the UK, the NHS National Institute for Health Research (NIHR 2014) has emphasised the value of patient and family involvement in all stages of research projects. According to NIHR (2014), such participation by patients or the public can highlight perspectives and clinical priorities that researchers had not considered. Therefore it is likely that future studies in end-of-life stroke care would be enhanced by involving patients and/or families from initial stages onwards.

Recall bias may have influenced the data from relatives, limiting the generalisability and transferability of the study. Conducting interviews within the optimum period of six months after bereavement (5.18.1.1) suggested by McPherson and Addington-Hall (2004) should have minimised the influence of recall bias. Media coverage of the LCP could also have influenced relatives' opinions about the LCP, creating further bias. Yet there was no evidence of such an influence because the views expressed by most participants did not reflect the largely negative tone of the coverage.

Since the LCP is now withdrawn in the UK, LCP-related findings are not transferable to other UK settings. Yet the study remains relevant for two reasons. First, families were primarily concerned with distressing stroke-related clinical issues rather than with LCP use. Such clinical issues are likely to persist as challenges in stroke care whether end-of-life care pathways are used or not, and the findings may be transferable to other stroke care settings in the UK and other countries with comparable stroke care services and patient groups. Second, in countries resembling Scotland culturally and in terms of health care, and where LCP use continues, findings from this study may be used to support LCP deployment in end-of-life stroke care.

Thus findings from this study relate to wider aspects of end-of-life stroke care and may be used in planning future care. The findings raise issues for clinical practice, education, policy and further research and these are considered in the next chapter.

Chapter 7 – Conclusion and recommendations

7.1 Introduction

In this chapter, the study methods, findings and contribution to knowledge are summarised. Thereafter conclusions are drawn and recommendations made for clinical practice, healthcare policy, education and further research.

7.2 Findings and contribution to knowledge

The aims of this study were to examine and compare clinical characteristics of stroke patients for whom the LCP was used or not used, investigate associated decision-making including the role of families, explore experiences of LCP use and explore outcomes of LCP use. A multi-centre mixed methods study was used to answer the research questions. In four Scottish acute stroke units, 100 casenotes were reviewed and 23 healthcare professionals and 17 bereaved relatives interviewed. Descriptive statistical analysis and logistic regression for quantitative data and a grounded theory approach to qualitative data analysis were used.

Previous investigations of the LCP in stroke care were limited to one LCP audit hence findings from this study contribute new understandings of end-of-life care pathway use in acute stroke units. This study was novel in exploring decision-making by comparing the characteristics of patients who died with or without LCP-based care. Although the LCP was called into disrepute following the UK media debate and the Neuberger review leading to its withdrawal in the UK, this study shows no evidence of LCP misuse. The study also contributes new knowledge on the process of decision-making, which was previously unreported. Finally, the study adds new knowledge regarding patient and family experiences of LCP-based care which were previously unexplored in a stroke context.

Integrating the analysed data for interpretation showed that decisions to use the LCP were unrelated to patients' demographic or clinical characteristics. Dying after stroke was recognised and managed in a consultative manner that included the views of the multidisciplinary stroke team and families while addressing barriers to decision-making such as weekend working patterns. Families influenced end-of-life care including decision-

making and relatives sometimes felt uncomfortably responsible for key decisions. Despite staff turnover healthcare professionals were trained in LCP use and care quality was commonly reported by families as good. Nevertheless relatives were unprepared for a prolonged dying process associated with severe dysphagia. Despite the diagnostic and decisional complexities of end-of-life stroke care, referrals to specialist palliative care services were rare. Families saw pro-active information-giving by staff as emotionally supportive, and a range of information formats were useful. Healthcare professionals seldom explored preferences for place of care, believing that patients were too sick and primary care services inadequate. Yet families who discussed the issue with the stroke team were satisfied with the outcome. Relatives suggested simple measures for bereavement support additional to those of the LCP model. Infrastructure limitations inhibited some aspects of end-of-life support for families.

Findings therefore indicated that end-of-life stroke care supported by the LCP was acceptable to patients, families and the clinical team although stroke-related aspects of dying remained to be addressed. While the study was specific to one geographical area and the LCP is now withdrawn in the UK, wider issues in end-of-life stroke care were identified. Implications and recommendations for future practice are now considered.

7.3 Recommendations for clinical practice

In this study, some aspects of good practice were identified in end-of-life stroke care and should continue. These related particularly to decision-making and ways in which information was imparted. Nevertheless practice relating to other aspects of care such as communicating uncertainty, discussing discharge or supporting the bereaved could be improved. Therefore the recommendations for clinical practice arising from this study are:

- Healthcare professionals should avoid giving families the impression that they must make decisions, but continue involving families in end-of-life decision-making in an informative capacity, in accordance with General Medical Council guidance.
- Where death is thought to be a likely outcome following acute stroke, healthcare professionals should communicate uncertain timescales clearly to families, including the possibility of a prolonged death for their relative.

- Where dying is prolonged, stroke unit staff should consider seeking support more frequently from specialist palliative care services, particularly for support with decision-making and symptom management.
- Healthcare professionals should ensure spoken as well as written information about end-of-life care is provided in acute stroke units, and signposting families to suitable online resources and other organisations should be considered.
- Access to senior medical staff for discussions should be made easy for relatives to navigate and modes of access explained clearly to families.
- Stroke unit staff should approach dying stroke patients and their families proactively with information on major and minor aspects of care. Families appreciate such information-giving on at least a daily basis.
- All staff should be open to discussing with families the issue of discharge for end-of-life care at home
- Stroke unit staff should consider best ways to provide bereavement support to families. This might include the offer of a follow-up consultation or locally-tailored practical information on returning medical equipment or accessing services.

7.4 Recommendations for health care policy

This study found no evidence to support the removal of the LCP from clinical areas. Nevertheless there are lessons to be learned from this study for organisational policy that applies to the UK where the LCP is withdrawn, and to other countries where LCP use continues. These are as follows:

- Clinical guidance on end-of-life care that replaces the LCP should encompass stroke-related issues such as varied trajectory, uncertainty of outcome and prolonged dying associated with intractable dysphagia.
- Clarity is required regarding weekend working. This applies in Scotland and the wider UK. If cover is provided by different teams across seven days, particularly in

respect of senior doctors, then policy needs to state how stroke unit teams should communicate. Communication should include a record of any discussions with families, any known patient preferences for end-of-life care, resuscitation status and agreed limits to treatment including feeding decisions.

- In countries where LCP use continues, clinical staff should be aware that not all stroke-related difficulties are addressed by the tool. The practice recommendations made in 7.3 pertain.
- Hospital managers should consider infrastructure in relation to end-of-life stroke care provided in their organisations. Adequate private space should be available for families of dying patients, including overnight accommodation.

7.5 Recommendations for education

The majority of staff participating in this study had received education on end-of-life care relating to the LCP model. The LCP model is now withdrawn in the UK yet for many healthcare professionals this was their only source of post-registration education on end-of-life care. Based on the findings of this study, the recommendations in relation to education are:

- A system of education and training on end-of-life care should be considered in stroke units to replace previous LCP training for staff.
- Education should be offered as a rolling programme to counteract attrition through staff turnover.

7.6 Recommendations for further research

Two issues that require further investigation arose from this study. These are as follows:

- Pro-active information giving is recommended. Future research could explore routes for such pro-active communication. For example, the effect of intentional information-rounding on patient and family satisfaction with communication could

be measured. This might enable clinicians to understand how best to approach patients and families.

- One of the original research questions for this study remains unanswered and is therefore recommended for future investigation. This was the third question relating to care of dying patients discharged to other settings. Therefore it would be useful to study end-of-life stroke care provided in non-stroke unit settings. Incidence, barriers, facilitators and patient and family experiences should be investigated.

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Appendix 1 – Typical documentation for the Liverpool Care Pathway (version 11), and sample family information sheet



Liverpool Care Pathway (Hospital Version)

Patient Name: CHI no: DOB:

Consultant Ward

General Practitioner	Telephone
District Nurse	Telephone
Macmillan Nurse	Telephone

Instructions for use

1. All goals are in **heavy** typeface. Interventions, which act as prompts to support the goals, are in normal type.
2. The palliative care guidelines are printed on the pages at the end of the pathway. Please make reference as necessary.
3. If you have any problems regarding the pathway contact the Palliative Care Team.

Practitioners are free to exercise their own professional judgement, however, any alteration to the practice identified within this LCP must be noted as a variance on the sheet at the back of the pathway.

Criteria for use of the LCP

Refer to algorithm found in resource folder / treatment areas

All possible reversible causes for current condition have been considered:

The multiprofessional team has agreed that the patient is dying, and two of the following may apply: -

The patient is bedbound	<input type="checkbox"/>	Semi-comatose	<input type="checkbox"/>
Only able to take sips of fluids	<input type="checkbox"/>	No longer able to take tablets	<input type="checkbox"/>

Doctor's Signature Date Time

Nurse's Signature Date Time

References:

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LCP Nov 2005-version 11

NHS Lanarkshire

Revised July 2010

Adapted from NHS Forth Valley and NHS Greater Glasgow & Clyde

1

[illegible]



Name: CHI no: Date/Time commenced:

Section 1	Initial assessment A = Achieved V = Variance If you chart "V" against any goal, please complete variance sheet			
Diagnosis & Demographics	PRIMARY DIAGNOSIS: SECONDARY DIAGNOSIS: DOB: Female <input type="checkbox"/> Male <input type="checkbox"/> Ethnicity:			
Physical condition Act to palliate any current symptoms / problems	Unable to swallow Nausea Vomiting Constipated Confused Agitation Restless Distressed	Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>	Aware Conscious UTI problems Catheterised Respiratory tract secretions Dyspnoea Pain Other (e.g. oedema, itch)	Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>
Comfort measures	Goal 1: Current medication assessed and non essentials discontinued Appropriate oral drugs converted to subcutaneous route and syringe driver commenced if appropriate. Inappropriate medication discontinued.			A <input type="checkbox"/> V <input type="checkbox"/>
	Goal 2: PRN subcutaneous medication written up for list below as per protocol (See sheets at back of LCP for guidance)			
	Pain Agitation Respiratory tract secretions Nausea & vomiting Dyspnoea	Analgesia Sedative Anticholinergic Anti-emetic Anxiolytic / Muscle relaxant	A <input type="checkbox"/> V <input type="checkbox"/> A <input type="checkbox"/> V <input type="checkbox"/> A <input type="checkbox"/> V <input type="checkbox"/> A <input type="checkbox"/> V <input type="checkbox"/> A <input type="checkbox"/> V <input type="checkbox"/>	A <input type="checkbox"/> V <input type="checkbox"/> A <input type="checkbox"/> V <input type="checkbox"/> A <input type="checkbox"/> V <input type="checkbox"/> A <input type="checkbox"/> V <input type="checkbox"/>
	Goal 3: Discontinue inappropriate interventions Blood test (including BM monitoring) Antibiotics I.V.'s (fluids/medications) Artificial hydration / nutrition Not for cardiopulmonary resuscitation recorded (Please record below & complete appropriate associated documentation - policy/procedure) Deactivate cardiac defibrillators (ICD's) Contact patient's Cardiologist Refer to local policy and procedures Information leaflet given to patient / carer if appropriate			A <input type="checkbox"/> V <input type="checkbox"/> N/A <input type="checkbox"/> A <input type="checkbox"/> V <input type="checkbox"/> N/A <input type="checkbox"/> A <input type="checkbox"/> V <input type="checkbox"/> N/A <input type="checkbox"/> A <input type="checkbox"/> V <input type="checkbox"/> N/A <input type="checkbox"/> A <input type="checkbox"/> V <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
	Doctor's signature: Date Time			
	Goal 3a: Decisions to discontinue inappropriate nursing interventions taken Routine turning regime – reposition for comfort only – consider pressure relieving mattress – & appropriate assessments re skin integrity - taking vital signs. If BM monitoring in place reduce frequency as appropriate e.g. once daily			Yes <input type="checkbox"/> No <input type="checkbox"/>
	Goal 3b: McKinley Pump set up within 4 hours of doctors order			Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
	Nurse signature: Date: Time:			



Name: CHI no: Date:

Section 1	
Initial assessment - Continued	
A = Achieved V = Variance	
If you chart "V" against any goal, please complete variance sheet	
Psychological/ insight	Goal 4: Ability to communicate in English assessed as adequate a) Patient A <input type="checkbox"/> V <input type="checkbox"/> Comatosed <input type="checkbox"/> b) Family/other A <input type="checkbox"/> V <input type="checkbox"/>
Record significant discussions in multidisciplinary notes page	Goal 5: Insight into condition assessed Aware of diagnosis a) Patient A <input type="checkbox"/> V <input type="checkbox"/> Comatosed <input type="checkbox"/> b) Family/other A <input type="checkbox"/> V <input type="checkbox"/> Recognition of dying c) Patient A <input type="checkbox"/> V <input type="checkbox"/> Comatosed <input type="checkbox"/> d) Family/other A <input type="checkbox"/> V <input type="checkbox"/>
Religious/ Spiritual support	Goal 6: Religious/spiritual needs assessed a) with Patient A <input type="checkbox"/> V <input type="checkbox"/> Comatosed <input type="checkbox"/> b) with Family/other A <input type="checkbox"/> V <input type="checkbox"/> Patient/other may be anxious for self/others Consider specific cultural needs Consider support of Chaplaincy Team Religious Tradition identified, if yes specify: A <input type="checkbox"/> V <input type="checkbox"/> N/A <input type="checkbox"/> Support of Chaplaincy Team offered A <input type="checkbox"/> V <input type="checkbox"/> In-house support Tel/bleep no: Name: Date/time: External support Tel/bleep no: Name: Date/time: Comments (Special needs now, at time of impending death, at death & after death identified)
Communication with family/other	Goal 7: Identify how family/other are to be informed of patient's impending death A <input type="checkbox"/> V <input type="checkbox"/> At any time <input type="checkbox"/> Not at night-time <input type="checkbox"/> Stay overnight at Hospital <input type="checkbox"/> Primary contact name: Relationship to patient: Tel no: Secondary contact: Tel no: Goal 8: Family/other given hospital information on:- A <input type="checkbox"/> V <input type="checkbox"/> Facilities leaflet available to address: Car parking; Accommodation; Beverage facilities; Payphones; Washrooms & toilet facilities on the ward; Visiting times; Any other relevant information.
Communication with primary health care team	Goal 9: G.P. Practice is aware of patient's condition A <input type="checkbox"/> V <input type="checkbox"/> G.P. Practice to be contacted if unaware patient is dying
Summary	Goal 10: Plan of care explained & discussed with: a) Patient A <input type="checkbox"/> V <input type="checkbox"/> Comatosed <input type="checkbox"/> b) Family/other A <input type="checkbox"/> V <input type="checkbox"/>
Record significant discussions in multidisciplinary notes page	Goal 11: Family/other express understanding of planned care A <input type="checkbox"/> V <input type="checkbox"/> Family/other aware that the planned care is now focused on care of the dying & their concerns are identified & documented. The LCP document may be discussed as appropriate
Nurse's Signature : Date: Time:	



Name: CHI no: Date:

Codes (please enter in columns) A= Achieved V=Variance (not a signature) If you chart "V" against any goal, please complete variance sheet If patient not symptom free, carry out appropriate intervention and reassess in 30 minutes							
Section 2	Patient problem/focus	04:00	08:00	12:00	16:00	20:00	24:00
Ongoing assessment Pain Goal: Patient is pain free <ul style="list-style-type: none"> Verbalised by patient if conscious Pain free on movement Appears peaceful Consider need for positional change 							
Agitation Goal: Patient is not agitated <ul style="list-style-type: none"> Patient does not display signs of delirium, terminal anguish, restlessness (thrashing, plucking, twitching) Exclude retention of urine as cause Consider need for positional change 							
Respiratory tract secretions Goal: Excessive secretions are not a problem <ul style="list-style-type: none"> Medication to be given as soon as symptoms arise Consider need for positional change Symptom discussed with family/other 							
Nausea & vomiting Goal: Patient does not feel nauseous or vomits <ul style="list-style-type: none"> Patient verbalises if conscious 							
Dyspnoea Goal: Breathlessness is not distressing for patient <ul style="list-style-type: none"> Patient verbalises if conscious. Consider need for positional change. 							
Other symptoms (e.g. oedema, itch)							
Treatment/procedures Mouth care Goal: Mouth is moist and clean <ul style="list-style-type: none"> See mouth care policy Mouth care assessment at least 4 hourly Frequency of mouth care depends on individual need Family/other involved in care given 							
Micturition difficulties(bladder problems) Goal: Patient is comfortable <ul style="list-style-type: none"> Urinary catheter if in retention Urinary catheter or pads, if general weakness creates incontinence 							
Medication (If medication not required please record as N/A) Goal: All medication is given safely & accurately <ul style="list-style-type: none"> If McKinley Pump in progress check at least 4 hourly according to monitoring sheet 							
Signature							



Name: CHI no: Date:

Codes (please enter in columns) A= Achieved V=Variance (not a signature) If you chart "V" against any goal, please complete variance sheet If patient not symptom free, carry out appropriate intervention and reassess		08:00	20:00
Mobility/Pressure area care	Goal: Patient is comfortable and in a safe environment <ul style="list-style-type: none"> Clinical assessment of: <ul style="list-style-type: none"> Skin integrity Need for positional change Need for special mattress Personal hygiene, bed bath, eye care needs 		
Bowel care	Goal: Patient is not agitated or distressed due to constipation or diarrhoea		
Psychological/Insight support Record significant discussions in multidisciplinary notes page	Patient Goal: Patient becomes aware of the situation as appropriate <ul style="list-style-type: none"> Patient is informed of procedures Touch, verbal communication is continued 		
	Family/other Goal: Family/other are prepared for the patient's imminent death with the aim of achieving peace of mind and acceptance <ul style="list-style-type: none"> Check understanding of nominated family/others / younger adults / children Check understanding of other family/others not present at initial assessment Ensure recognition that patient is dying & of the measures taken to maintain comfort Chaplaincy Team support offered 		
Religious/Spiritual support	Goal: Appropriate religious/spiritual support has been given <ul style="list-style-type: none"> Patient/other may be anxious for self/others Support of Chaplaincy Team may be helpful Consider cultural needs 		
Care of the family/others	Goal: The needs of those attending the patient are accommodated <ul style="list-style-type: none"> Consider health needs & social support. Ensure awareness of ward facilities 		
Nurse's Signature Early: Late: Night:			

Repeat Continuous Evaluation every 24 hours

Spare sheets available as required.

Visits by members of MDT team and specific discussions should be recorded in multidisciplinary notes page at back of LCP



Name: CHI no: Date:

SECTION 3: Care After Death

Date of death: Time of death:

Persons present:

Notes:

Signature:

Care after death	Goal 12: GP Practice contacted re patient's death Date __/__/__ • If out of hours contact on next working day Message can be left with receptionist	A <input type="checkbox"/>	V <input type="checkbox"/>
	Goal 13: Procedures for laying out followed according to hospital policy • Carry out specific religious / spiritual / cultural needs - requests	A <input type="checkbox"/>	V <input type="checkbox"/>
	Goal 14: Procedure following death discussed or carried out Check for the following: • Explain mortuary viewing as appropriate • Family aware cardiac devices (ICD's) or pacemaker must be removed prior to cremation • Post mortem discussed as appropriate. Ensure Death Certificate completed Complete Cremation Form – part 1 • Input patients death on hospital computer	A <input type="checkbox"/>	V <input type="checkbox"/>
	Goal 15: Family/other given information on hospital procedures • Information booklet given to family/other about necessary legal tasks •	A <input type="checkbox"/>	V <input type="checkbox"/>
	Goal 16: Hospital policy followed for patient's valuables & belongings • Belongings and valuables are signed for by identified person • Property packed for collection. • Valuables listed and stored safely	A <input type="checkbox"/>	V <input type="checkbox"/>
	Goal 17: Necessary documentation & advice is given to the appropriate person • 'What to do after death' booklet given (DHSS)	A <input type="checkbox"/>	V <input type="checkbox"/>
	Goal 18: Bereavement leaflet given • Information leaflet on grieving and local support given	A <input type="checkbox"/>	V <input type="checkbox"/>
	If you have charted "V" against any goal so far, please complete variance sheet at the back of the pathway before signing below Health Professional signature: Date:		



What Variance occurred & why?	Action Taken	Outcome
Signature..... Date/Time.....	Signature..... Date/Time.....	Signature..... Date/Time.....
Signature..... Date/Time.....	Signature..... Date/Time.....	Signature..... Date/Time.....
Signature..... Date/Time.....	Signature..... Date/Time.....	Signature..... Date/Time.....

Liverpool Care Pathway for the Dying Patient (LCP) - supporting care in the last hours or days of life

Information sheet to be given to the relative or carer following a discussion regarding the plan of care.

The doctors and nurses will have explained to you that there has been a change in your relative or friend's condition. They believe that the person you care about is now dying and in the last hours or days of life.

The LCP is a document which supports the doctors and nurses to give the best quality of care. All care will be reviewed regularly.

You and your relative or friend will be involved in the discussion regarding the plan of care with the aim that you fully understand the reasons why decisions are being made. If your relative or friend's condition improves then the plan of care will be reviewed and changed. All decisions will be reviewed regularly. If after a discussion with the doctors and nurses you do not agree with any decisions you may want to ask for a second opinion.

Communication

There are information leaflets available for you as it is sometimes difficult to remember everything at this sad and challenging time. The doctors and nurses will ask you for your contact details, as keeping you updated is a priority.

Medication

Medicine that is not helpful at this time may be stopped and new medicines prescribed. Medicines for symptom control will only be given when needed, at the right time and just enough and no more than is needed to help the symptom.

Comfort

The doctors and nurses will not want to interrupt your time with your relative or friend. They will make sure that as far as possible any needs at this time are met. Please let them know if you feel those needs are not being met, for whatever reason.

You can support care in important ways such as spending time together, sharing memories and news of family and friends.

**Information sheet to be given to the relative or carer
continued:**

Reduced need for food and drink

Loss of interest in and a reduced need for food and drink is part of the normal dying process. When a person stops eating & drinking it can be hard to accept even when we know they are dying. Your relative or friend will be supported to eat and drink for as long as possible. If they cannot take fluids by mouth, fluids given by a drip may be considered.

Fluids given by a drip will only be used where it is helpful and not harmful. This decision will be explained to your relative or friend if possible and to you.

Good mouth care is very important at this time. The nurses will explain to you how mouth care is given and may ask if you would like to help them give this care.

Caring well for your relative or friend is important to us. Please speak to the doctors or nurses if there are any questions that occur to you, no matter how insignificant you think they may be or how busy the staff may seem. This may all be very unfamiliar to you and we are here to explain, support and care.



We can be reached during daytimes at:

Night time at:

Other information or contact numbers (e.g. palliative care nurse / district nurse):

.....
.....
.....

This space can be used for you to list any questions you may want to ask the doctors and nurses:

.....
.....

Appendix 2 – Views of Informal Carers: Evaluation of Services (VOICES II) questionnaire tool

Section D

These questions are about his last admission to hospital. If his last admission was for less than 24 hours, please answer these questions about a previous admission which was for more than 24 hours.

D1) Did he stay in hospital at any time during his last three months of life for more than 24 hours?

- | | |
|--------------------------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No, not for more than 24 hours | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

If 'Yes', what was the name of this hospital?

If 'Yes', please continue with the questions below.

If 'No' please go to section E (page 20).

D2) On this occasion, do you feel he was discharged at the right time?

- | | |
|--|--------------------------|
| He was not discharged, he died on this admission | <input type="checkbox"/> |
| Yes, he was discharged at the right time | <input type="checkbox"/> |
| No, he was discharged too soon | <input type="checkbox"/> |
| No, he was discharged too late | <input type="checkbox"/> |

Please comment if you would like to:

D3) During his last hospital admission, how often were you or Other family members kept informed about his condition?

- Always ☐
- Usually ☐
- Sometimes ☐
- Never ☐
- Don't know ☐

D4) During his stay, did the hospital doctors and nurses explain his condition, treatment or tests in a way that you found easy or difficult to understand?

- Very easy ☐
- Fairly easy ☐
- Fairly difficult ☐
- Very difficult ☐
- They did not explain his condition, treatment or tests to me ☐
- I never saw a doctor/nurse ☐

D5) While he was in hospital, did doctors and nurses give you any information about his condition, treatments or tests in a way that upset you?

- Yes ☐
- No ☐
- I did not talk to any hospital doctors or nurses ☐

Please comment if you would like to:

D6) Were you able to discuss with doctors, nurses or other hospital staff any worries or fears you might have had about his condition, treatment or tests?

I had no worries or fears to discuss ☐

Yes, I discussed them as much as I wanted ☐

Yes, I discussed them but not as much as I wanted ☐

No, although I tried to discuss them ☐

D7) In your opinion, were there enough nurses on duty to care for him in hospital?

There were always or nearly always enough nurses on duty ☐

There were sometimes enough nurses on duty ☐

There were rarely or never enough nurses on duty ☐

Don't know ☐

D8) Did you have confidence and trust in the nurses who were caring for him?

Yes, in all of them ☐

Yes, in some of them ☐

No, not in any of the nurses ☐

D9) During this stay, was there enough help available to meet his personal care needs, such as bathing, dressing, help with eating, and going to the bathroom?

Yes ☐

No ☐

Don't know ☐

D10) How much of the time was he treated with respect and dignity by the doctors, nurses and other hospital staff?

Always ☐

- | | |
|------------------|--------------------------|
| Most of the time | <input type="checkbox"/> |
| Some of the time | <input type="checkbox"/> |
| Never | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

D11) During this last hospital admission, how involved were you with the decisions made about his care?

- | | |
|-----------------|--------------------------|
| Very involved | <input type="checkbox"/> |
| Fairly involved | <input type="checkbox"/> |
| Not involved | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

D12) Were you involved in decisions about his treatment and care as much as you wanted?

- | | |
|--------------------------------------|--------------------------|
| Involved as much as I wanted | <input type="checkbox"/> |
| Would have liked to be more involved | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |
| Not applicable | <input type="checkbox"/> |

Please comment if you would like to:

D13) During this last hospital admission, was there any decision made about his care or treatment that he would not have wanted?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

Please comment if you would like to:

Please feel free to comment further on any aspect of the care received in hospital:

Section F

The questions are concerned with his experiences in the last three days of his life and the care he received.

F1) During his last three days was he:

- | | |
|---|--------------------------|
| At home all the time | <input type="checkbox"/> |
| In a nursing or residential home all the time | <input type="checkbox"/> |
| In hospital all the time | <input type="checkbox"/> |
| In a hospice all the time | <input type="checkbox"/> |
| Other (<i>please comment</i>) | |

If he was in more than one place, please answer the following questions about the place he spent the most time.

F2) During these last three days, was there enough help available to meet his personal care needs, such as bathing, dressing, help with eating, and going to the bathroom?

- | | |
|-----|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |

Don't know ☐

F3) During these last three days, was there enough help with nursing care, such as getting dressings changed and with medication?

Yes ☐

No ☐

Don't know ☐

Not applicable ☐

F4) During these last three days, how involved were you with the decisions made about his care?

Very involved ☐

Fairly involved ☐

Not involved ☐

Not applicable ☐

F5) Were you involved in decisions about his treatment and care as much as you wanted?

Involved as much as I wanted ☐

Would have liked to be more involved ☐

Don't know ☐

Not applicable ☐

F6) During these last three days, was there any decision made about his care or treatment that he would not have wanted?

Yes ☐

No ☐

Don't know ☐

Please comment if you would like to:

F7) During these last three days, was there any decision made about his

care or treatment that you did not want?

Yes ☐

No ☐

Don't know ☐

Please comment if you would like to:

F8) During these last three days, did it seem likely that he would die very soon?

Yes ☐

No ☐

Don't know ☐

Please comment if you would like to:

F9) Many people are unconscious or drowsy towards the end of their life. Was he:

(please tick all that apply)

Unconscious all of the time ☐

Unconscious some of the time ☐

Drowsy all of the time ☐

Drowsy some of the time ☐

None of these ☐

F10) Did he have any pain in his last three days of life?

Yes ☐

No ☐

Don't know ☐

F11) Do you think that it distressed or bothered him?

Yes ☐

No ☐

Don't know ☐

Not applicable, he did not have any pain ☐

F12) Did he have any treatment for his pain?

Yes ☐

No ☐

Don't know ☐

Not applicable, he did not have any pain ☐

F13) Did the treatment relieve him pain:

Completely all of the time ☐

Completely some of the time ☐

Partially ☐

Not at all ☐

Don't know ☐

Not applicable, he did not have any pain ☐

F14) Did he have any breathlessness in his last three days of life?

Yes ☐

No ☐

Don't know ☐

Not applicable, he did not have any breathlessness ☐

F15) Do you think his breathlessness distressed or bothered him?

Yes ☐

No ☐

Don't know ☐

Not applicable, he did not have any breathlessness ☐

F16) Did he have any treatment for his breathlessness?

Yes ☐

No ☐

Don't know ☐

Not applicable, he did not have any breathlessness ☐

F17) Did the treatment relieve his breathlessness:

Completely all of the time ☐

Completely some of the time ☐

Partially ☐

Not at all ☐

Don't know ☐

Not applicable, he did not have any breathlessness ☐

F18) Please comment, if you would like to, on any symptoms he may have had and any help he may have received for these:

Please feel free to comment further on any aspect of the care received:

Section G

The following questions are about the circumstances surrounding his death, and your feelings about the way in which health and social services treated you both at this time.

G1) Where did he die?

- | | |
|--|--------------------------|
| In his own home | <input type="checkbox"/> |
| In the home of another family member or friend | <input type="checkbox"/> |
| Hospital | <input type="checkbox"/> |
| Hospice | <input type="checkbox"/> |
| Residential/nursing home | <input type="checkbox"/> |
| On the way to hospital/hospice | <input type="checkbox"/> |
| Other (<i>please explain below</i>): | |

G2) Were you with him when he died?

- | | |
|-----|--------------------------|
| Yes | <input type="checkbox"/> |
|-----|--------------------------|

No

☐

Please comment if you would like to:

G3) On balance, do you feel that he died in the right place?

Yes, it was the right place

☐

No, it was not the right place

☐

Not sure

☐

Don't know

☐

G4) If 'No', was it because:

It was not where he wanted to die

☐

The care he received there was poor

☐

He was too far away from family and friends

☐

Not applicable

☐

Other

☐

(Please comment if you would like to):

G5) Were you told that he was likely to die shortly?

Yes

☐

No

☐

If 'Yes' please continue with the questions below

If 'No' please go to question G9

G6) Were you given a chance to talk about this at the time?

Yes ☐

No ☐

Don't know ☐

G7) Did you feel you had enough privacy when you were told?

Yes ☐

No ☐

Don't know ☐

G8) Were you told in a way that upset you?

Yes ☐

No ☐

Don't know ☐

Please comment if you would like to:

G9) Did you know what to expect when he was dying?

Yes ☐

Yes, partially ☐

No ☐

Don't know ☐

Please comment if you would like to:

G10) Do you feel that his personal and religious beliefs were taken into consideration by those caring for him?

Yes ☐

No ☐

Don't know ☐

Please comment if you would like to:

The next few questions are about your experiences following his death.

G11) Would you have liked another chance to discuss his death with those involved in his care?

Yes ☐

No ☐

Not sure ☐

G12) Since he died, have you talked to anyone from health or social services or from a bereavement service about your feelings regarding his illness and death?

Yes ☐

No ☐

If 'No', would you have liked to talk to someone?

Yes ☐

No ☐

Don't know ☐

If 'Yes', who did you speak to?_____

Please comment if you would like to:

G13) Was that talk helpful?

- | | |
|----------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |
| Not applicable | <input type="checkbox"/> |

G14) Is there any other help or support you would have liked from health or social services since his death?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

Please feel free to comment further on any aspect of the care received:

Appendix 3 – Approval letter from West of Scotland Multicentre NHS Research Ethics Committee

WoSRES
West of Scotland Research Ethics Service



West of Scotland REC 2
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhsggc.org.uk

Ms Eileen Cowey
Research Assistant
University of Glasgow
Nursing & Health Care
59 Oakfield Avenue
Glasgow G12 8LL

Date 18th August 2011
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Ms Cowey

Study title: Impact of a dying care pathway on end of life care following stroke
REC reference: 11/WS/0024
Protocol number: n/a

The Research Ethics Committee reviewed the above application at the meeting held on 16 August 2011. Thank you for attending to discuss the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Discussion

- 1) The Committee agreed that the main issue was recruitment, i.e. the family was being approached when their relative was being admitted and asked if they would be happy to be contacted in 3 to 6 months to take part in the study but they would not be given any written information at that point. The Committee had concerns that families may not realise that their relative was terminally ill. In discussion you advised that the clinical team would identify patients placed on the LCP and then either a member of the clinical team or a Research Nurse would approach the relatives to establish whether they would be happy to be contacted at a later date to take part in the study. You also confirmed that the family would have already been informed by the clinical team of the likely outcome and that their relative had been placed on the pathway. The Committee preferred that the clinical team make the first approach in view of the sensitivities.
- 2) The Committee agreed that some of the questions were of a sensitive nature and could cause distress. You advised that you had read and consulted widely on this subject and taken advice from other Researchers.
- 3) The Committee also asked what safeguards were in place should someone become upset because their experience was not handled appropriately at the time and may now feel aggrieved. You advised that there were no specific safeguards in place and may be this should have been part of the exclusion criteria.

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- 4) The Committee asked whether it was intended to have single or group interviews, or a mixture of both for the Health Professionals. You advised that Health Professionals would be given the choice but commented that it was easier to speak to the Doctors in a group and the Nurses one at a time.
- 5) The Committee asked whether it was intended to compare patients not on the LCP with those on the pathway. You advised that there were no plans to go down this route.
- 6) The Committee asked that the web page link stated in the Participant Information Sheet be checked as some Members could not access this.
- 7) The Participant Information Sheet should have contact details at the beginning. There should also be details of an independent contact. This should be someone who knows about the study, can speak to participants or give advice but must not be involved in the study.
- 8) The Committee took the view that it was not necessary to inform the GP.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Other conditions specified by the REC

- a) Please confirm that the clinical team will make the first approach in view of the sensitivities. Also consider giving the families some written information about the study at the initial approach.

- b) Please advise what safeguards will be put in place should an aggrieved relative who may be recruited to the study become distressed.
- c) The Participant Information Sheets to be amended as follows:
- Contact details to be at the beginning
 - The web page link to be checked for accuracy and corrected if required.
 - Details of an independent contact to be included
 - Reference to the GP being informed to be removed
- d) The Consent Forms to have contact details at the beginning.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	-	22 July 2011
Evidence of insurance or indemnity	-	09 August 2010
GP/Consultant Information Sheets	1	12 July 2011
Interview Schedules/Topic Guides	1	12 July 2011
Investigator CV	-	17 June 2011
Letter from Statistician	-	22 March 2011
Letter of invitation to participant	Relatives v1	12 July 2011
Letter of invitation to participant	Health Care Professionals v1	12 July 2011
Other: Professor Lorraine Smith's CV	-	
Other: Consent for contact	1	12 July 2011
Other: Dr D Stott	-	
Other: Demographic Details for Relatives	1	12 July 2011
Other: Demographic Details for Health Care Professionals	1	12 July 2011
Other: Letter re. funding for project	-	16 December 2010
Participant Consent Form: For relatives	1	12 July 2011
Participant Consent Form: For Health Care Professionals	1	12 July 2011
Participant Information Sheet: For relatives	1	12 July 2011
Participant Information Sheet: For Health Care Professionals	1	12 July 2011
Protocol	1	12 July 2011
Questionnaire: Voices II	-	
REC application	-	13 July 2011

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/WS/0024	Please quote this number on all correspondence
-------------------	---

With the Committee's best wishes for the success of this project

Yours sincerely


Liz Jamieson
Committee Co-ordinator
On behalf of Dr Jesse Dawson, Acting Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
 "After ethical review – guidance for researchers"

Copy to: Dr Erica Packard, R&D – NHS Greater Glasgow & Clyde

Appendix 4 – Researcher letter of response to Ethics committee



University
of Glasgow

College of Medical, Veterinary
& Life Sciences
Nursing & Health Care School

Evelyn Jackson
Coordinator, Committee 2
West of Scotland Research Ethics Service
Ground floor
The Tennent Institute
Western Infirmary
38 Church St
Glasgow
G11 6NT

28 August 2011

Dear Ms Jamieson

Study title: Impact of a dying care pathway on end of life care following stroke

REC reference: 11/WS/0024

Thank you for your letter of 18 August, indicating the Committee's favourable ethical opinion.

Regarding Discussion point 3, I did not intend to convey to the Committee that intention to complain/feeling aggrieved on the part of families "maybe should have been part of the exclusion criteria" as your letter states. Rather, I stated that this was not part of our exclusion criteria. We will seek to speak to all willing participants and will address safeguards as outlined in b) below.

Regarding the conditions specified:

We are seeking management permission (R&D approval) via the National Research Scotland Permissions Co-ordinating Centre and submitted an application on 22nd July.

Other conditions specified by the REC:

a) The clinical team will make the first approach to relatives. In addition, as requested we have considered giving families written information about the study at the initial approach. Bearing in mind that families are likely to receive other written information at this time, we will supply written details about the study on request. This is to avoid overloading families with information at a distressing time.

b) In our application we outlined safeguards that we will put in place should an interview participant become distressed. As requested, we will add in the safeguard that should an aggrieved relative become distressed, the researcher will provide them with details of the relevant NHS complaints team to contact (see Appendix 1).

c) We amended the Participant Information Sheets as follows (copies enclosed):

- contact details moved to the beginning
- web linked was checked and is accurate
- details of an independent contact were added
- reference to informing the GP was removed

d) Contact details have been added at the beginning of consent forms.

With best wishes,

Yours sincerely

A handwritten signature in black ink that reads "Eileen Cowey". The script is cursive and fluid, with the first name "Eileen" and last name "Cowey" clearly distinguishable.

Eileen Cowey MN, BN, RN
Research Assistant

Appendix 5 - Final approval letter from Ethics committee

WoSRES
West of Scotland Research Ethics Service



West of Scotland REC 2
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhsqgc.org.uk

Ms Eileen Cowey
Research Assistant
University of Glasgow
Nursing & Health Care
59 Oakfield Avenue
Glasgow
G12 8LL

Date 9th September 2011
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Ms Cowey

Full title of study: Impact of a dying care pathway on end of life care following stroke
REC reference number: 11/WS/0024

Thank you for your letter of 5th September 2011. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 16 August 2011. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter		05 September 2011
Other: Amendment to Question A22		
Participant Consent Form: Relatives	2	28 August 2011
Participant Consent Form: Healthcare Professionals	2	28 August 2011
Participant Information Sheet: Relatives	2	28 August 2011
Participant Information Sheet: Health Professionals	2	28 August 2011

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

11/WS/0024	Please quote this number on all correspondence
------------	--

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Yours sincerely


Mrs Liz Jamieson
Committee Co-ordinator

Copy to: Dr Erica Packard, NHS Greater Glasgow and Clyde

Appendix 6 – Letters granting NHS Research & Development approvals in each health board area



Coordinator/Administrator: Dr Erica Packard/Mrs Elaine O'Neill
Telephone Number: 0141 211 6208
E-Mail: erica.packard@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor 38 Church Street
Glasgow, G11 6NT,

15 September 2011

Dr Christine McAlpine
Dept of Medicine for the Elderly
Glasgow Royal Infirmary
Glasgow
G4 0SF

NHS GG&C Board Approval

Dear Dr McAlpine,

Study Title:	Impact of a dying care pathway on end of life care following stroke
Principal Investigator:	Dr Christine McAlpine
GG&C HB site	Glasgow Royal Infirmary & Western Infirmary
Sponsor	NHS Greater Glasgow and Clyde
R&D reference:	GN11NE251
REC reference:	11/WS/0024
Protocol no:	V1; 12/07/11
<small>(including version and date)</small>	

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information relating to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

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Page 1 of 2

R&D Approval GN11NE251

2. **For all studies** the following information is required during their lifespan.
- a. Recruitment Numbers on a quarterly basis
 - b. Any change of staff named on the original SSI form
 - c. Any amendments – Substantial or Non Substantial
 - d. Notification of Trial/study end including final recruitment figures
 - e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,



Dr Erica Packard
Research Co-ordinator



Ms Eileen Cowey
Research Assistant
University of Glasgow
59 Oakfield Avenue
Glasgow
G12 8LL

R&D Department
Corporate Services Building
Monklands Hospital
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date 15 September, 2011
Enquiries to Margaret Stewart,
R&D Facilitator
Direct Line 01236 712445
Email Margaret.stewart@lanarkshire.scot.nhs.uk

Dear Ms Cowey,

PROJECT TITLE: Impact of a dying care pathway on end of life care following stroke

R&D ID NUMBER: L11066

NRS ID NUMBER : NRS11/NR16

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

NAME	TITLE	ROLE	NHSL SITE TO WHICH APPROVAL APPLIES
Dr Brian MacInnes	Consultant Stroke and COTE	Local Collaborator / Principal Investigator	Hairmyres Hospital

For the study to be carried out you are subject to the conditions outlined overleaf:

Cont/...

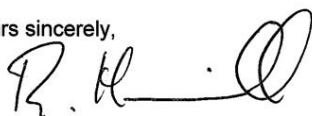
Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and the Data Protection Act 1998.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: <http://www.show.scot.nhs.uk/cso/> or the Research & Development Intranet site: <http://firstport/sites/randd/default.aspx>).
- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.
- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the R&D Department if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire.
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Cont/...

Yours sincerely,



Raymond Hamill
Research & Development Manager

cc.

NAME	TITLE	CONTACT ADDRESS	ROLE
Dr Brian MacInnes	Consultant Stroke and COTE	Hairmyres Hospital	Principal Investigator / Local Collaborator
Dr Erica Packard		NHS Greater Glasgow & Clyde – R&D Department	Sponsor Contact

c.c – (email)

nhsgr.nrscc@nhs.net

University Hospitals Division

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

DEN/JK/approval

23 September 2011

Dr Gillian E Mead
Senior Lecturer in Geriatric Medicine, Room
F1642
Royal Infirmary of Edinburgh
51 Little France Crescent
Edinburgh
EH16 4SA



Research & Development
Room E1.12
Tel: 0131 242 3330
Fax: 0131 242 3343

Email:

R&DOOffice@luht.scot.nhs.uk

Director:

Professor David E Newby

Dear Dr Mead,

Lothian R&D Project No: **2011/R/ME/02**

Title of Research: Impact of a dying care pathway on end of life care following stroke

REC No: 11/WS/0024

CTA No: N/A

Eudract: N/A

PIS: Version 2, 28 August 2011

Consent: Version 2, 28 August 2011

Protocol No: Version 1 dated 12 July 2011

I am pleased to inform you that this study has been approved for NHS Lothian and you may proceed with your research, subject to the conditions below. This letter provides Site Specific approval for NHS Lothian.

We note that this Project includes researchers who will require a Clinical Research Access letter from NHS Lothian. The individuals concerned should contact our offices with a view to applying for the necessary documentation. **Please note all final paperwork will have to be signed and returned to the R&D Office before a researcher can commence work on a project.**

Please note that the NHS Lothian R&D Office must be informed if there are any changes to the study such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS Lothian. This includes any changes made subsequent to management approval and prior to favourable opinion from the REC.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please inform this office when recruitment has closed and when the study has been completed.

I wish you every success with your study.

Yours sincerely

A handwritten signature in black ink, appearing to read 'David Newby', with a stylized flourish at the end.

Professor David E Newby
R&D Director

Cc: Ms Eileen Cowey, Research Assistant, University of Glasgow

Appendix 7 – Letter of advice from Ethics Committee scientific officer

WoSRES

West of Scotland Research Ethics Service

West of Scotland Research Ethics Service

Ground Floor – The Tennent Institute

Western Infirmary

38 Church Street Glasgow

G11 6NT

Ms Eileen Cowey
Research Assistant
Nursing & Health Care School
School of Medicine
University of Glasgow
57-61 Oakfield Avenue
G12 8LL

Date	23/8/11
Your Ref	
Our Ref	WoS ASD 616
Direct line	0141 211 2126
Fax	0141 211 1847
E-mail	Judith.Godden@ggc.scot.nhs.uk

Dear Ms Cowey

Full title of project: **The Impact of a Dying Care Pathway on Care at the End of Life Following a Stroke**

You have sought advice from the West of Scotland Research Ethics Service Office on Part 1 of the above project. This has been considered by the Scientific Officer and you are advised that it does not need ethical review under the terms of the Governance Arrangements for Research Ethics Committees (REC) in the UK. The advice is based on the following.

- Part 1 of the project is an audit using only data obtained as part of usual care but note the requirement for Caldicott Guardian approval to permit sharing or publication of anonymised data obtained from patient under the care of NHS Scotland.

If during the course of your project the nature of the study changes and starts to generate new knowledge and thereby inadvertently becoming research then the changing nature of the study would necessitate REC review at that point, before any further work was undertaken. A REC opinion would be required for the new use of the data collected.

Note that this advice is issued on behalf of the West of Scotland Research Ethics Service Office and does **not** constitute a favourable opinion from a REC. It is intended to satisfy journal editors and conference organisers and others who may require evidence of consideration of the need for ethical review prior to publication or presentation of your results.

However, if you, your sponsor/funder or any NHS organisation feels that the project should be managed as research and/or that ethical review by a NHS REC is essential, please write setting out your reasons and we will be pleased to consider further.

Where NHS organisations have clarified that a project is not to be managed as research, the Research Governance Framework states that it should not be presented as research within the NHS. This letter has been copied to NHS Greater Glasgow & Clyde R&D Department for their information.

Kind regards

Dr Judith Godden, WoSRES Scientific Officer/Manager

Appendix 8 – Approval letter from University of Glasgow College of Medical, Veterinary and Life Sciences Ethics Committee



University of Glasgow | College of Medical,
Veterinary & Life Sciences

Eileen Cowey
Nursing & Health Care School
School of Medicine
College of Medical, Veterinary & Life Sciences
59 Oakfield Avenue
University of Glasgow
G12 8LL

18 September 2011

Dear Ms Cowey

MVLS College Ethics Committee

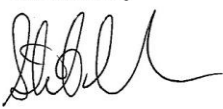
Project Title: The impact of a dying care pathway on care at the end of life following stroke

Project No: FM 08127

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. They are happy therefore to approve the project, subject to the following conditions

- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- If the study does not start within three years of the date of this letter, the project should be resubmitted.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely


Dr David Shaw
College Ethics Officer

Dr D Shaw
Lecturer in Ethics & Ethics Officer

School of Medicine, University of Glasgow, 378 Sauchiehall
Street, Glasgow, G2 3JZ

Tel: 0141 211 9755

E-mail: david.shaw@glasgow.ac.uk

Appendix 9 – Approvals from Caldicott data guardians in each health board area



Application for Caldicott Guardian approval for use of patient identifiable data (PID)

Audit / Project Title

Impact of a dying care pathway on end of life care following stroke

Details of individual / organisation requesting data

Internal: Professor David Stott, Honorary Consultant, NHS GG&C/University of Glasgow
Eileen Cowey, RN, Honorary Contract NHS GG&C/University of Glasgow

External: Professor Lorraine N Smith, University of Glasgow

Purpose for which data are to be used

Data will be used to audit end of life care following stroke.

It is planned to conduct a 12-month prospective casenote audit of stroke patients receiving end of life care in the stroke units at Glasgow Royal Infirmary and the Western Infirmary.

All information recorded will be anonymised. No identifiable information will leave the health board.

The University of Glasgow College of Medical, Veterinary and Life Sciences Ethics Committee has given approval for this work to be included as part of a PhD (Appendix 1).

Which identifiable data items are required?

Forename ☒ Surname ☒ DoB ☐ Age ☒ Sex ☒ Address ☐
Post code ☐ Clinical Information ☒ Other ☒ (please provide further details below)

Other: CHI number, hospital number

Please justify why each identifiable data item is required

Age: We need to record age to build a patient profile.
Sex: As above.
Clinical information: We need to record some clinical data to audit the end of life care received by stroke patients.
Forename, surname, CHI number, hospital number: A hard copy written record is needed to allow retrieval of case records.

Who will have access to this information?

Internal: Professor D Stott (DS), Eileen Cowey (EC), Dr Christine McAlpine (CMcA), Professor Matthew Walters (MW)

External: Professor Lorraine Smith (LNS).

The written data needed for case record retrieval will be stored in a locked cabinet on the NHS site.

Identifiable audit data will be anonymised for recording (EC). Anonymised hard copy audit sheets may be accessed by DS, CMcA, MW or LNS for supervisory purposes. The anonymised data will be stored in a database on a password-protected computer, in a locked office at the University of Glasgow. Custodial arrangements will meet with University of Glasgow policy, including password protection of files, backed up daily to a secure central server. Access will be restricted to EC.

The Scottish Stroke Research Network (SSRN) has adopted this project and statistical support may be available. Any data transferred for statistical analysis will be anonymised and transferred subject to SSRN security procedures, with access restricted to the SSRN statistical management team.

DS and LNS will supervise the analysis and reporting of findings. Findings will be reported in peer reviewed journals and via conference presentations.

Storage and use of personal data during the audit/project

Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)

- ☒ Access to medical records
- ☒ Electronic transfer by magnetic or optical media, email or computer networks*
- ☐ Sharing of personal data with other organisations
- ☐ Publication of data that might allow identification of individuals
- ☐ Use of audio/visual recording devices
- ☐ Storage of personal identifiable data on any of the following:
 - ☒ Manual files, including x-rays
 - ☐ NHS Computers
 - ☐ Home or other personal computers
 - ☐ University computer
 - ☐ Private company computer
 - ☐ Laptop computers

*** Additional Information:**

Any data transferred for statistical analysis will be anonymised and will be transferred subject to the Scottish Stroke Research Network security procedures.

Please list your organisation's Data Protection Registration Number
(If external to NHSGGC)

Z6723578

Person responsible for the requested data

Name: Eileen Cowey

Job Title: Research Assistant

Signature:

Eileen Cowey

Date: 06 October 2011

Note:

- Please provide copies of any other relevant supporting documentation (e.g. ethics approval, patient information leaflet etc.)
- Appendix A details the Caldicott Principles

The release of data as described above is: **approved / not approved**

Caldicott Guardian

Brown

Date: 26/10/11

Application for Caldicott Guardian approval for use of patient identifiable data (PID)

You must address the 6 Caldicott Principles (Appendix A) when submitting this request for data

1. Audit/Project Title

Impact of a dying care pathway on end of life care following stroke

2. Details of individual/organisation requesting data

Internal: Dr Brian MacInnes, Consultant, NHS Lanarkshire
Eileen Cowey, RN, Honorary Contract NHS Lanarkshire/University of Glasgow

External: Professor Lorraine N Smith, University of Glasgow

3. Purpose for which data are to be used (Principle 1)

Data will be used to audit end of life care following stroke. This is an important area for audit because stroke remains a national clinical priority (Scottish Government (2007) Better health, better care: action plan) and the Scottish Government is committed to supporting implementation of high quality end of life care in all care settings (*Living & Dying Well*, Scottish Government, 2008).

It is planned to conduct a 12-month prospective casenote audit of stroke patients receiving end of life care in the stroke unit at Hairmyres Hospital.

All information recorded will be anonymised. No identifiable information will leave the health board.

The University of Glasgow College of Medical, Veterinary and Life Sciences Ethics Committee has given approval for this work to be included as part of a PhD (Appendix 1).




4. Outline why it is necessary to use identifiable data for this project. (Principle 2)









It is necessary to use identifiable data for this project because:

- care cannot be audited otherwise
- suitable secondary data are not available
- they are needed to build a profile of patients receiving end of life care in line with Scottish Government policy (*Living & Dying Well*, Scottish Government, 2008)

Data will be anonymised for recording, analysis and reporting.

5. Which identifiable data items are required? Outline the reasons for using each individual item of PID. (Principle 3)

PID required	Why necessary
Chi Number 	A hard copy written record is needed to allow retrieval of case records.
Forename 	As above
Surname 	As above

Other (specify) 	Hospital number. Reason as for items above.
Initials 	
DoB 	
Age 	We need to record age to build a patient profile.
Gender 	We need to record gender to build a patient profile.
Address 	
Post code 	
Clinical Information 	We need to record some clinical data to audit the end of life care received by stroke patients.
(Please provide any further details below)	

6. Please provide full details of individuals who will have access to this identifiable data. (Principle 4)

Internal: Dr Brian MacInnes, Eileen Cowey

External: Professor Lorraine Smith.

The written data needed for case record retrieval will be stored in a locked cabinet on the NHS site. Identifiable audit data will be anonymised for recording by Eileen Cowey. Dr MacInnes or Professor Smith may access anonymised hard copy audit sheets for supervisory purposes.

7. How will this identifiable data be kept secure from any further individuals? (Principle 4)

The anonymised data will be stored in a database on a password-protected computer, in a locked office at the University of Glasgow. Custodial arrangements will meet with University of Glasgow policy, including password protection of files, backed up daily to a secure central server. Access will be restricted to Eileen Cowey.

The Scottish Stroke Research Network (SSRN) has adopted this project and statistical support may be available. Any data transferred for statistical analysis will be anonymised and transferred subject to SSRN security procedures, with access restricted to the SSRN statistical management team.

Professor Smith will supervise the analysis and reporting of findings. Findings will be reported in peer-reviewed journals and via conference presentations.

8. Outline action taken to ensure compliance with responsibilities and obligations to respect patient confidentiality e.g. individual policies or training. (Principle 5)

Data will be handled in accordance with the Data Protection Act (1998) and with the NHS Confidentiality Code of Practice (2003). This means:

- The auditor will only collect as much information as is needed
- Data will be stored securely in an anonymised form
- Data will be stored only as long as needed, in line with the University of Glasgow Code of Good Practice in Research (2007) and with Caldicott Guardian guidance.

9. If you are not from NHS Lanarkshire outline who has statutory responsibility for information governance within your organisation? (Principle 6)

The University's Data Protection Officer can be contacted as follows:
email: data.protection@gla.ac.uk
tel: +44 (0)141 330 3111/5146
post: Data Protection Office, Gilbert Scott Building, University of Glasgow, Glasgow G12 8QQ

Please list your organisation's Data Protection Registration Number (if external to NHS Lanarkshire)

Z6723578

Person responsible for the requested data

Name: Eileen Cowey

Job Title: Research

Assistant

Signature:  **Date:** 23/11/2011

Note:

Please provide copies of any other relevant supporting documentation (e.g. ethics approval, patient information leaflet etc.)

✂

The release of data as described above is:

Approved ☒ **Not approved** 

Caldicott Guardian: 

Date: 24/11/11

Dr Harpreet Kohli, Director of Public Health and Health Policy

Lothian NHS Board

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 465 5461
Fax 0131 536 465 5494



www.nhslothian.scot.nhs.uk

Ms Eileen Cowey
Research Assistant
Nursing and Health Care School
School of Medicine, University of Glasgow
57-61 Oakfield Avenue
GLASGOW, G12 8LL

Date 31st October 2011
Your Ref
Our Ref JMS/fb/11199
Enquiries to Jim Sherval
Extension
Direct Line 0131 465 5461
Email jim.sherval@nhslothian.scot.nhs.uk

Dear Ms Cowey

CALDICOTT APPLICATION 11199

Impact of a dying care pathway on end of life care following stroke

Thank you for the information supplied

Request received from	Eileen Cowey, Research Assistant, Nursing & Health Care School, Glasgow University
Summary of proposal	Impact of a dying care pathway on end of life care following stroke
Patient identifiable information requested	CHI Number, Forename, Surname, Age, Gender, Other (Clinical Information and Hospital Number)
Approved	YES
Advice	

Yours sincerely

Dr Alison McCallum
Director of Public Health & Health Policy



Headquarters
Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG

Chair Dr Charles J Winstanley
Chief Executive Professor James J Barbour O.B.E.
Lothian NHS Board is the common name of Lothian Health Board

Appendix 10 – Data extraction tool for casenote review



University
of Glasgow

College of Medical, Veterinary
& Life Sciences
Nursing & Health Care School



Key: Codes for boxes ☐ Yes [Y]; No [N]; Unknown [?]; Not recorded [NR]; Ambiguous/illegible [#]; Not applicable [NA]

Background	
Study site (please circle)	Site A/Site B/Site C/Site D
Sex (please circle)	M/F
Age	
Date of admission to hospital	Insert date:
Date of admission to stroke unit of study	Date recorded <input type="checkbox"/> Insert date:
Date of first stroke symptom	Date recorded <input type="checkbox"/> Insert date:
Is this a first stroke?	<input type="checkbox"/>
Number of previous strokes	Insert number:
Co-morbidities documented (circle all that apply)	<input type="checkbox"/> Tumour (last 5 years)//lymphoma /leukaemia / solid tumour with metastases peripheral vascular disease/myocardial infarction / congestive cardiac failure connective tissue disease/ulcer disease/COPD / renal disease – moderate or severe / diabetes / diabetes with end organ damage / dementia / liver disease –mild, moderate or severe / AIDS
CT scan	<input type="checkbox"/> Insert date:
Stroke pathology (please circle)	Ischaemic / Haemorrhagic / Haemorrhagic transformation of infarct / Uncertain / Not recorded
OCSF classification (by most senior clinician, on admission) (please circle)	TACS / PACS / POCS / LACS / Not documented Insert date:
Side of brain affected (please circle)	Left / Right / Bilateral / Not known Not documented
Site/territory of stroke (circle all that apply)	MCA / Malignant MCA syndrome / Brainstem Other (specify)
NIHm score recorded	<input type="checkbox"/> Specify score:
Barthel recorded	<input type="checkbox"/> Specify score:

Case Mix	
Was the patient independent in Activities of Daily Living (ADL) before the current event?	<input type="checkbox"/>
In their normal place of residence did the patient live alone?	<input type="checkbox"/>
Can the patient talk at first assessment?	<input type="checkbox"/>
Is the patient orientated to time, place and person at first assessment?	<input type="checkbox"/>
Can the patient lift both arms off the bed at first assessment?	<input type="checkbox"/>
Is the patient able to walk without help from another person?	<input type="checkbox"/>

Acute management	
Swallow screen recorded for current event?	<input type="checkbox"/> Date recorded <input type="checkbox"/> Insert date:
Was aspirin given in hospital following current event?	<input type="checkbox"/> Date recorded <input type="checkbox"/> Insert date:
If N to aspirin, was alternative antiplatelet given?	<input type="checkbox"/> Date recorded <input type="checkbox"/> Insert date: clopidogrel / dipyridamole
Thrombolysis	<input type="checkbox"/> Date recorded <input type="checkbox"/> Insert date:
Clot retrieval procedure	<input type="checkbox"/> Date recorded <input type="checkbox"/> Insert date:
Decompressive surgery	<input type="checkbox"/> Date recorded <input type="checkbox"/> Insert date:

Care pathway	
Was end of life considered to be a possibility in relation to this stroke event?	<input type="checkbox"/> Specify:
Was end of life anticipated within next few hours or days?	<input type="checkbox"/>
Date anticipation is recorded	<input type="checkbox"/> Enter date: Enter time:
Was use of LCP/equivalent considered?	<input type="checkbox"/>
Do notes specify a justification for considering use of LCP/equivalent?	<input type="checkbox"/>
Details of justification: (circle all that apply)	Stroke severity/neuro deterioration/ cardiovascular deterioration/ renal failure/sepsis/other:
On LCP form, were 'criteria for use' boxes ticked?	<input type="checkbox"/> Tick if no boxes on form <input type="checkbox"/> Bedbound / semi comatose / no longer able to take tablets / only able to take sips of fluid
Was LCP/equivalent used?	<input type="checkbox"/> Date begun is recorded <input type="checkbox"/>

	Insert date: _____ Time: _____
LCP/equivalent discontinued <i>(Repeat as necessary)</i>	<input type="checkbox"/> Date discontinued is recorded <input type="checkbox"/> Insert date: _____ Time: _____
If LCP/equivalent not used, is reason documented?	<input type="checkbox"/> List reasons: _____
GP informed patient is dying	<input type="checkbox"/>
Decision not to commence (i.e. to withhold) treatment or investigations other than CPR is documented	Y/N Specify: non-essential routine drugs, enteral feeding, vital signs, antibiotics, blood tests, clinically assisted hydration, oxygen therapy, glucose monitoring
Decision to discontinue (i.e. to withdraw) treatment or investigations is documented	Y/N Specify: non-essential routine drugs, vital signs, antibiotics, blood tests, clinically assisted hydration, oxygen therapy, glucose monitoring
NFR/DNR written in casenotes (not formal doc)	<input type="checkbox"/> Insert date _____
Formal DNACPR documentation completed	<input type="checkbox"/> Insert date _____
Evidence of symptom assessment (circle all that were present) <i>RTS = respiratory tract secretions</i>	<input type="checkbox"/> Pain, agitation, RTS, nausea & vomiting, dysphagia, dyspnoea, hiccups, distress, other (specify) _____
If 'yes', has action been taken to alleviate symptoms?	<input type="checkbox"/>
Is there evidence that action to alleviate symptoms has been reviewed?	<input type="checkbox"/>
Non essential oral drugs have been stopped If 'no' record reason	<input type="checkbox"/> List reasons: _____
Prescription of PRN drugs for:	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <i>See sheet at back of LCP for guidance</i>
Route prescribed: (circle all routes that apply)	Oral/intravenous/nasogastric/PEG tube/subcutaneous intermittent dose/subcutaneous syringe driver/other: _____
Was PRN medication administered?	<input type="checkbox"/>
Were intravenous fluids in progress at time of death?	<input type="checkbox"/>
Was enteral feeding considered?	<input type="checkbox"/>
Was enteral feeding given?	<input type="checkbox"/> Route: NG / PEG
Date feeding started	Insert date: _____
Latest date feeding stopped	Insert date: _____
Reason feeding stopped	Planned <input type="checkbox"/> Feed not tolerated / not in best interests

(circle all that apply)	Unplanned <input type="checkbox"/> Tube pulled out / tube fell out
Next of kin: Name recorded	<input type="checkbox"/>
Contact number	<input type="checkbox"/>
If no next of kin, is another contact documented?	<input type="checkbox"/> specify: Friend/carers/neighbour
Clearly recorded if family want to be contacted overnight?	<input type="checkbox"/> <input type="checkbox"/>
Name of contact and contact number are clear	
Was palliative care service involved with patient?	<input type="checkbox"/>
Patient ability to communicate assessed?	<input type="checkbox"/>
Specify: (circle all that apply)	Aphasia/cognitive difficulties/ unconscious/confused/translator required / able to communicate/ other:
Were staff able to communicate with family?	<input type="checkbox"/> Additional info: interpreter required/family member could interpret/ deafness/other:
Was patient aware of end of life diagnosis?	<input type="checkbox"/>
Was family/other aware of end of life diagnosis?	<input type="checkbox"/>
Evidence that family/carers were involved in decision to use LCP/equivalent	<input type="checkbox"/>
Plan of care discussed with patient	<input type="checkbox"/>
Plan of care discussed with family	<input type="checkbox"/>
Family express understanding of plan of care	<input type="checkbox"/>
Religious tradition clearly recorded	<input type="checkbox"/>
Religious/spiritual needs* assessed with patient <i>*what is important to them at this time: wishes, beliefs, values</i>	<input type="checkbox"/>
Religious/spiritual needs assessed with family	<input type="checkbox"/>
Hospital chaplaincy team (or similar) contacted	<input type="checkbox"/>
Adults with Incapacity (Scotland) Act 2000 invoked	<input type="checkbox"/>
If yes to AWISA above, who is legal representative for patient?	Relative/friend/medical consultant / other(specify):
Family given hospital information (accommodation, car parking, dining facilities)	<input type="checkbox"/>
Procedure following death discussed or carried out (circle all that apply)	<input type="checkbox"/> Viewing of body, post mortem discussed, policy followed re. collection patient valuables
Family/other given death certificate	<input type="checkbox"/>
Advice leaflet given (What to do after a death in Scotland)	<input type="checkbox"/>
Bereavement booklet given	<input type="checkbox"/>
Outcome	
Discharged to: home or sheltered/care home/NHS continuing care/ rehabilitation/ acute hospital/died/other	Enter date: Enter time:

Data collected by: _____

Date of data collection: _____

Appendix 11 – Record of consent given by relatives to be contacted about the study



University of Glasgow | Nursing & Health Care



Care at the End of life following Stroke

Consent for contact

Name of relative: _____

Address: _____

Postcode: _____

This relative has given verbal consent to me that they may be contacted for the above study.

Signed: _____

Designation: _____

Date: _____

Copy to casenotes
Copy for SSRN

Consent for contact- NHS GG&C| v1 12 07 2011

Appendix 12 - Letter of invitation to bereaved relatives



University of Glasgow | Nursing & Health Care



Date:

Dear

A few months ago we let you know that we might be contacting you to invite you to participate in a research study on care at the end of life following stroke.

The study is happening because we want to ensure that the best care is being provided for patients at the end of life and their relatives. We are now writing to invite you to take part in the study, which would involve one interview with you about your experiences.

The enclosed information explains the study. If you would like to take part please complete the consent form enclosed and return it in the prepaid envelope provided (no stamp needed) or you may contact Eileen Cowey directly on 0141 330 2069. If no-one is available, please leave a message and she will contact you as soon as possible. Alternatively you can email her at eileen.cowey@glasgow.ac.uk.

Participation in this study is completely voluntary. Not taking part in this study will in no way affect the standard of care you receive from the NHS.

We would like to reassure you that this study has received ethics approval.

Eileen Cowey will be very happy to answer any questions you may have.

Yours sincerely,

.....
(Consultant's signature)
On behalf of the Care Team

.....
Eileen Cowey
Research Assistant
Nursing & Health Care School
59 Oakfield Avenue
University of Glasgow
Glasgow, G12 8LL

Appendix 13 – Participant Information Sheet for bereaved relatives



University of Glasgow | Nursing & Health Care



Participant Information Sheet

Information about this study may be obtained from:

Eileen Cowey, Research Assistant
Nursing & Health Care School, 59-61 Oakfield Avenue
University of Glasgow, Glasgow, G12 8LL
0141 330 2069
eileen.cowey@glasgow.ac.uk

Study title: Care at the End of life following Stroke

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

Who is conducting the research?

Professor Lorraine N Smith from the Nursing & Health Care School at the University of Glasgow is leading the research. Eileen Cowey is a Registered Nurse working in the same department, and she is carrying out this research as part of her PhD thesis.

Who has reviewed the study?

This study has been approved by the West of Scotland Research Ethics Committee and by the Research & Development Departments of NHS Greater Glasgow & Clyde, NHS Lanarkshire and NHS Lothian.

What is the purpose of the study?

The study will run for two years and will consist of casenote reviews and interviews with staff and relatives/carers.

We would like to hear about your experiences of the care that your relative, friend or loved one received. Ultimately, we want to ensure that patients at the end of life, and their families, feel supported and cared for during this time.

Why have I been invited to participate?

We are contacting relatives, friends or loved ones of patients who died in hospital following their stroke. If you feel that it would be more appropriate for us to contact someone else please let us know.

Do I have to take part?

It is up to you to decide. You do not have to take part in this study if you don't want to. If you decide to participate you are still free to withdraw at any time and without giving a reason, either before or during the interview. This will not be known to anyone apart from yourself and the research team.

If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. For further independent information about taking part in research check http://www.nhs24.com/content/default.asp?page=s3_15_5 or ask the researcher for a printout. Alternatively, you may contact Dr Lorna Paul via 0141 330 3526.

What will happen to me if I take part?

You will be invited to take part in an interview, which will last around 45-60 minutes. The researcher will contact you by phone or email to arrange the interview. The interview will be arranged for a time and place that is convenient for you.

The researcher will ask some questions about the services and care which you and your relative, friend or loved one received during their time in hospital. The researcher will record some of your answers on paper and some on an audio-recorder. The audio-record and the paper document will not be marked with any personal details, and both will be stored securely. Within three months of the study ending the recording will be deleted. We can provide you with an electronic or paper copy of the audio-record if you so wish.

Can I have someone with me during the interview?

Yes, although the questions will be for you.

Confidentiality

Your identity and personal information will be completely confidential and known only to the researchers. All data will be collected and stored in accordance with the Data Protection Act 1998. This means that all of the information we collect will be treated as confidential. We will make sure that information is stored in an anonymous form (this means that your information will not be stored in a way that means it can be linked directly to you). The data for this study will be stored securely at the University of Glasgow and will not be available to anyone outside the research team.

As part of the research reporting process some parts of the interview may be used to illustrate findings from the study. However please be assured that nothing that could reveal your identity will be disclosed.

What are the possible advantages of taking part?

It is very important for researchers and healthcare professionals to know the views of bereaved people such as you so that services can be provided appropriately. We hope that you may find it helpful to have an opportunity to talk about your experiences.

What are the possible disadvantages or risks of taking part?

Some people find that thinking or talking about their situation makes them upset or sad. The researcher will be able to reassure you if you become distressed, and if you wish you will be able to take a break, or to stop the interview at any point. A list of bereavement support services will be available from the researcher.

Giving informed consent to take part

If you would like more information about the study or wish to discuss this further before making a decision, please contact me (Eileen Cowey) on 0141 330 2069 or email eileen.cowey@glasgow.ac.uk. I will be happy to answer any questions you may have.

If you would like to take part in the study please contact me by phone or email. Or you can sign and return the attached consent form to me in the reply-paid envelope.

Please note that before the interview you will be asked to read the statements on the consent form attached and you will have an opportunity to ask further questions. You will then be asked to sign the consent form, or if you already signed, to reaffirm your consent to show that you agree to participate.

We will give you a copy of the information sheet and signed consent form to keep.

If you have a complaint about any aspect of the study

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint mechanisms are also available to you.

Will I be informed about the findings of the study?

A final report on the study will be written for Chest, Heart & Stroke Scotland. If you would like to receive a summary of the report, please tell the researcher.

Travel costs

If you need to make a local journey to an interview we will reimburse your reasonable travel costs.

Thank you for your time and co-operation

Appendix 14 – Consent form: relatives



University of Glasgow | Nursing & Health Care



Contact details:

Eileen Cowey, 59-61 Oakfield Avenue
University of Glasgow, Glasgow, G12 8LL
0141 330 2069
eileen.cowey@glasgow.ac.uk

Participant number:

Care at the End of Life Following Stroke

Consent form

I confirm that I have read and understand the information sheet dated 28 August 2011 (version 2) for the above study and have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

I agree to take part in the above study.

☐

I agree to the use of anonymised quotes in publications.

☐

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

1 copy to the participant, 1 copy to the researcher

Consent form for relatives NHS GG&C| v2 28 08 2011

Appendix 15 – Letter of invitation to healthcare professionals



University of Glasgow | Nursing & Health Care



Date:

Dear Colleague

Study title: Care at the End of Life Following Stroke

I am writing to invite you to take part in a study of experiences with end of life care pathways. The information gathered will be used to understand and support decision making in end of life stroke care. We hope that this study will help to improve the experience of care for people following a stroke.

I enclose an information leaflet that provides details of the study and what your participation would involve. Please read the information carefully. If you would like more information before deciding whether to participate or if you would like to take part in the study please contact me by phone or email. You can reach me at 0141 330 2069 or eileen.cowey@glasgow.ac.uk . If there is no-one available, please leave a message and I will contact you as soon as possible. I will be very happy to answer any questions you may have.

Alternatively you can sign and return the attached consent form to me via internal mail or by post.

Yours sincerely,

Eileen Cowey, Registered Nurse
Research Assistant
Nursing & Health Care School
59-61 Oakfield Avenue
University of Glasgow
Glasgow, G12 8LL
0141 330 2069

eileen.cowey@glasgow.ac.uk

Letter of invitation for health care professionals NHS GG&C | v1 12 07 2011

Appendix 16 – Participant Information Sheet for healthcare professionals



University of Glasgow | Nursing & Health Care



Information about this study may be obtained from:

Eileen Cowey, Research Assistant
Nursing & Health Care School, 59-61 Oakfield Avenue
University of Glasgow, Glasgow, G12 8LL
0141 330 2069

eileen.cowey@glasgow.ac.uk

Participant Information Sheet

Study title: Care at the End of Life Following Stroke

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

Who is conducting the research?

Professor Lorraine N Smith from the Nursing & Health Care School at the University of Glasgow is leading the research. Eileen Cowey is a Registered Nurse working in the same department. She is carrying out this research as part of her PhD thesis and will collect the data.

Who has reviewed the study?

This study has been approved by the West of Scotland Research Ethics Committee and by the Research & Development Departments of NHS Greater Glasgow & Clyde, NHS Lanarkshire and NHS Lothian.

What is the purpose of the study?

The study will run for two years and will consist of casenote reviews and interviews with staff and relatives/carers.

We are interested in knowing whether using an end of life care pathway improves care delivery from the family/carers and professional point of view. The study aims to describe the implementation of the LCP in Scottish stroke units and to examine the clinical decision making involved in placing a stroke patient on the LCP. We will examine the impact of the LCP/equivalent on patients, bereaved relatives/carers and the multidisciplinary team involved in the care of stroke patients.

Why have I been invited to participate?

You have been asked to take part because you are working in an Acute Stroke Unit where the Liverpool Care Pathway is in use and may have experience of using the LCP.

Do I have to take part?

It is up to you to decide. You do not have to take part in this study if you don't want to. If you decide to participate you are still free to withdraw at any time and without giving a reason, either before or during the interview. This will not be known to anyone apart from yourself and the research team. For further independent information about taking part in research check http://www.nhs24.com/content/default.asp?page=s3_15_5 or ask the researcher for a printout. Alternatively, you may contact Dr Lorna Paul via 0141 330 3526.

What will happen to me if I take part?

If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form to show that you agree to take part. You will be invited to take part in an interview, which will last approximately 30 minutes. The researcher will contact you to arrange the interview. The interview will be arranged for a time and place that is convenient for you and may take place with a few of your colleagues. If you prefer, the interview can be held in your own time rather than when you are on duty. The researcher will ask some questions about your views on the use end of life care pathways and their influence on practice.

With your permission the researcher will digitally record your answers to have an accurate account of what is discussed. The recording will not be labelled with any personal details and will be stored in a locked cabinet. Within three months of the study ending the recording will be deleted. The researcher can provide you with an electronic or paper copy if you wish.

Confidentiality

Your identity, place of work and personal information will be completely confidential and known only to the researchers. All data will be collected and stored in accordance with the Data Protection Act 1998. This means that all of the information we collect will be treated as confidential. We will make sure that information is stored in an anonymous form (this means that your information will not be stored in a way that means it can be linked directly to you). Data for this study will be stored securely at the University of Glasgow and will not be available to anyone outside the research team.

As part of the research reporting process some parts of the interviews may be used to illustrate the study findings. However please be assured that nothing that could reveal your identity will be disclosed.

What are the possible advantages of taking part?

While there is no benefit to you personally, we hope to improve our understanding of the challenges facing staff who deliver end of life care in stroke units.

Giving informed consent to take part

If you would like more information about the study or wish to discuss this further before making a decision, please contact Eileen Cowey on 0141 330 2069 or email eileen.cowey@glasgow.ac.uk. Eileen will be happy to answer any questions you may have.

If you would like to take part in the study please contact me by phone or email. Or you can sign and return the attached consent form to me via internal mail or by post.

Please note that before the interview you will be asked to read the statements on the consent form attached and you will have an opportunity to ask further questions. You will then be asked to sign the consent form, or if you already signed, to reaffirm your consent to show that you agree to participate.

We will give you a copy of the information sheet and signed consent form to keep.

If you have a complaint about any aspect of the study

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint mechanisms are also available to you.

Will I be informed about the findings of the study?

A final report on the study will be written for Chest, Heart & Stroke Scotland. If you would like to receive a summary of the report, please tell the researcher.

Travel costs

If you need to make a local journey to an interview we will reimburse your reasonable travel costs.

Thank you for your time and co-operation

Appendix 17 – Consent form for healthcare professionals



University of Glasgow | Nursing & Health Care



Contact details:

Eileen Cowey, 59-61 Oakfield Avenue
University of Glasgow, Glasgow, G12 8LL
0141 330 2069
eileen.cowey@glasgow.ac.uk

Participant number:

Care at the End of Life Following Stroke

Consent form

I confirm that I have read and understand the information sheet dated 28 August 2011 (version 2) for the above study and have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

☐

I agree to take part in the above study.

☐

I agree to the use of anonymised quotes in publications.

☐

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

1 copy to the participant, 1 copy to the researcher

Appendix 18 – New version - record of verbal consent for family to be contacted by the researcher



University of Glasgow | Nursing & Health Care



Care at the End of life following Stroke

Verbal consent for contact

Name of relative: _____

Relative's address: _____

Postcode: _____

This relative has given me verbal consent that they may be contacted for the above study by the researcher.

Signed: _____

Designation: _____

Date: _____

Copy to casenotes
Copy for SSRN

Consent for contact- NHS GG&C| v2 06 12 2011

Appendix 19 - Staff information poster for display in duty rooms



University of Glasgow | Nursing & Health Care



Study on End of Life Care after Stroke

Attention all trained staff

Are you using the LCP for a stroke patient?

- ✓ Please ask the family if I may contact them about the study (in the future)
- ✓ If they agree, please complete the verbal consent form (in LCP pack) with name & address of family contact
- ✓ You sign form and leave in casenotes

Many thanks!

Eileen Cowey, RN
Study co-ordinator
0141 330 2069

eileen.cowey@glasgow.ac.uk

Poster for staff NHS GG&C| v1 13 12 2011

Appendix 20 – Ethics committee approval letter for minor amendment

WoSRES
West of Scotland Research Ethics Service



West of Scotland REC 2
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhsggc.org.uk

Ms Eileen Cowey
Research Assistant
University of Glasgow
Nursing & Health Care
59 Oakfield Avenue
University of Glasgow
G12 8LL

Date 16th January 2012
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Ms Cowey

Study title: Impact of a dying care pathway on end of life care following stroke
REC reference: 11/WS/0024
Amendment number: AM01
Amendment date: 13 December 2011

Thank you for your email of 13 December 2011, notifying the Committee of the above amendment, i.e. a Poster to be displayed in Duty Rooms.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	Version	Date
Poster	1	13 December 2012
Notification of a Minor Amendment	AM01	13 December 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/WS/0024:	Please quote this number on all correspondence
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Yours sincerely

Mrs Liz Jamieson
Committee Co-ordinator

Appendix 21 – Initial guide for interviews with bereaved relatives



Care at the End of Life Following Stroke

Interview guide - interviews with relatives/carers

Openers

- How are you?
- How have things been since your relative died?
- Are there any issues arising from the VOICES questionnaire that you would like to discuss?

Care

- What did you think of the care received?
- What do you know about the Liverpool Care Pathway?

Decision making

- How involved did you feel in making decisions?
- Is there anything you think could have been done differently?

Appendix 22 – Initial guide for interviews with healthcare professionals



Care at the End of Life Following Stroke

Interview guide - interviews with healthcare professionals

Begin by clarifying that the interview is about stroke patients only, not Care of the Elderly patients in general.

Opening question:

Can you start by telling me about your experiences of providing end of life care after stroke?

Focused questions:

How do you know when a stroke patient is in the last hours or days of their life? *Prompt - Examinations/assessments/signs/symptoms*

So how does it come about, that a patient is started on an end-of-life care pathway? How is the decision made? *Prompts: Who raises issue? Who makes the decision to use the LCP? To what extent is the MDT involved? The family? How long does it take to come to a decision?*

How do you find out the concerns/wishes of the patient?

What can you tell me about your communication with families? *Prompts - How it happens – appointments/ Visiting time/ Visitors' rounds? What information do you give?*

What practical or emotional support is available for relatives? *Prompts - Private space for discussions, overnight accommodation, parking, written info, spiritual care?*

What about input from palliative care services for your stroke patients?

Can you tell me about situations where stroke patients are dying but are not on the LCP? *Prompts*
- *Why would LCP not be used? What is care like? Is it different?*

What can you tell me about feeding stroke patients who are in the last stages of their lives?

What can you tell me about stroke patients going home for end of life care? (Or to a nursing home?) *Prompts - How do families feel about it? Do you raise it with families?*

What education is available for staff?

How long are patients usually on the pathway for?

What is the usual eventual outcome in your experience? *(Timescale)*

There has been coverage of the LCP in the media which families may be aware of. What's your experience?

Closing questions:

LCP Impact

- Overall, how has using the LCP/equivalent affected your own practice? Practice in your stroke unit? *Prompt - Has it changed the way staff talk about/handle dying)*
- What do you think the effect of end-of-life care pathway use has been for patients? For families?

Finally, is there something I haven't asked you that you'd like to talk about?

Appendix 23 – Final guide for interviews with bereaved relatives



Care at the End of Life Following Stroke Guide for interviews with relatives/carers

Opener:

- How are you?
- How have things been since your relative died?
- Can you start by telling me about your – and your relative's – experiences of end-of-life care after the stroke?

Care:

- What did you think of the care received? *Prompt – Physical comfort? Emotional support?*
- What did you understand about the plan of care for your relative?
- What do you know about the Liverpool Care Pathway?

Decision making:

- How involved did you feel in communicating? *Prompt – With your relative? With staff?*
- How involved did you feel in making decisions? *Prompt – Feeding? Resuscitation?*
- What did you understand about your relative's diagnosis?

Practical:

- What practical help or advice were you given? *Prompt – Leaflets? Accommodation? How helpful was that?*

Spiritual:

- What was important to you and your relative at that time? *Prompts – Wishes? Beliefs?*

Closing questions:

- Is there anything you think could have been done differently?
- Is there something that we haven't mentioned that you would like to talk about?

Appendix 24 – Final guide for interviews with healthcare professionals, showing items (highlighted) added to explore emerging issues



Begin by clarifying that the interview is about stroke patients only, not Care of the Elderly patients in general.

Opening question:

Can you start by telling me about your experiences of providing end of life care after stroke?

Focused questions:

How do you know when a stroke patient is in the last hours or days of their life? *Prompt - Examinations/assessments/signs/symptoms*

So how does it come about, that a patient is started on an end-of-life care pathway? How is the decision made? *Prompts: Who raises issue? Who makes the decision to use the LCP? To what extent is the MDT involved? The family? How long does it take to come to a decision?*

How do you find out the concerns/wishes of the patient?

What can you tell me about your communication with families? *Prompts - How it happens – appointments/ Visiting time/ Visitors' rounds? What information do you give?*

What practical or emotional support is available for relatives? *Prompts - Private space for discussions, overnight accommodation, parking, written info, spiritual care?*

What about input from palliative care services for your stroke patients?

Can you tell me about situations where stroke patients are dying but are not on the LCP? *Prompts*
- *Why would LCP not be used? What is care like? Is it different?*

In the course of this study I have come across instances where staff use principles laid out in the LCP but the LCP is not formally commenced. What is your experience of this? *Prompts - Which LCP principles are addressed? Which are not?*

Can you tell me about weekends and deciding to use the LCP?

What can you tell me about feeding stroke patients who are in the last stages of their lives?

What can you tell me about stroke patients going home for end of life care? (Or to a nursing home?) *Prompts - How do families feel about it? Do you raise it with families?*

What education is available for staff?

How long are patients usually on the pathway for?

What is the usual eventual outcome in your experience? *(Timescale)*

There has been coverage of the LCP in the media which families may be aware of. What's your experience?

Closing questions:

LCP Impact

- Overall, how has using the LCP/equivalent affected your own practice? Practice in your stroke unit? *Prompt - Has it changed the way staff talk about/handle dying)*
- What do you think the effect of end-of-life care pathway use has been for patients? For families?

Finally, is there something I haven't asked you that you'd like to talk about?

Appendix 25 – Permission to use VOICES II questionnaire

From: Young A.J. <A.J.Young@soton.ac.uk>
Sent: 16 August 2011 09:44
To: Eileen Cowey
Subject: RE: VOICES II survey

Dear Eileen

Apologises for the very late response

I cannot foresee a problem using the VOICES II tool face to face. Although it was adapted so that people could complete the questionnaire without having face to face contact with the research team it can be completed as a structured interview process. If anything, more detail could come from face to face administration

Again apologies and if I can be of assistance please do contact me - flag as important so it gets picked up in my email account. Otherwise you run the risk of me losing the email.

Best wishes,
Amanda

Research Fellow
University of Southampton's Wessex Institute
Ex: 25598
Email: A.J.Young@southampton.ac.uk

25 April 2023
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Appendix 27 – Lay summary of the study



Care at the end of life after stroke Research summary

Who did the study and why?

This study was carried out by nurses and doctors from the University of Glasgow, the University of Edinburgh and from the NHS.

We aimed to look at the care that people received at the end of their lives after a stroke. We did this to make sure that patients and their families feel supported and cared for during this time.

What research did we do?

We interviewed 17 family members of patients who died after their stroke. We also interviewed 23 doctors, nurses, nursing assistants and speech therapists. Around the same time, we looked at casenotes of 100 patients who died after their stroke. We held interviews in several hospitals in Scotland and interviewed people in their own homes.

How long did the study last?

The study took two years to complete.

This was a sensitive topic. Were people upset by taking part?

We are very grateful to everyone who took part in the study. Some people did find it upsetting but many found it helpful to talk about their experiences.

What did we find out?

We asked about staff and families about their experiences, including where the Liverpool Care Pathway was used. We found that:

- Most relatives were pleased with the care received
- There were some concerns about unsatisfactory communication.
- Families found it helpful and caring when staff came to them directly with information about their relative.
- Families were often involved in making decisions about their relative's care.
- Families were happy to tell doctors and nurses about their relative's wishes and preferences. This helped the staff to make decisions about care.
- However, families were uncomfortable if they felt solely responsible for making decisions.

- Families were particularly distressed when their loved one experienced a very long period of end of life care. This happened especially where feeding was difficult or impossible.
- Families thought about taking their relative home for end of life care more than doctors and nurses realised.
- In our patient group we found no evidence that the Liverpool Care Pathway had been misused.

How will this help to improve care?

From our findings, we are suggesting some ways to improve care. These include:

- Stroke unit staff of all grades can help to support families by approaching families personally with updates and information about their relative
- The stroke team should involve families in making decisions about care. However the team should avoid giving the families the impression they are being asked to make major care decisions
- The stroke team should talk clearly to families about uncertainties, including the possibility of a prolonged dying process after stroke.

Who will we tell?

We are contacting the families and stroke teams who took part to let them know our findings. We presented the findings at health care conferences and published them in the journal *Palliative Medicine* in September 2014.

What has happened since the study?

Since the study finished, the UK and Scottish governments have recommended that the Liverpool Care Pathway should be withdrawn. The UK government ran a consultation asking for people's views on how end of life care should change. We contributed some views arising from this study.

Who funded this research?

This research was funded by the charity Chest Heart & Stroke Scotland.

Further information

If you would like further information you can contact:

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59 Oakfield Ave
University of Glasgow
G12 8LL

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